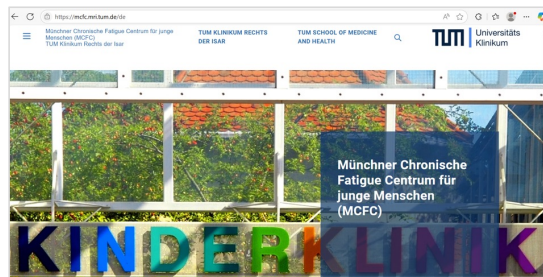


Pediatric Network for Medical Care and Research of Long COVID-like Diseases (LC), including COVID-19 Sequelae (PASC), Similar Post-acute Infection and Vaccination Syndromes (PAIVS), and ME/CFS (PEDNET-LC)

Uta Behrends

Munich Chronic Fatigue Center for Young People (MCFC)
mcfc.kinderklinik@mri.tum.de



m^{ck}
MÜNCHEN
KLINIK



Universitäts
Klinikum

Zentrum für Kinder- und Jugendmedizin: Eine Kooperation
von München Klinik und TUM Klinikum



PEDNET-LC

Gefördert durch:



Bundesministerium
für Gesundheit

12/2024 - 12/2028

aufgrund eines Beschlusses
des Deutschen Bundestages

Conflicts of Interest

Committee Work

- Working Group Post-Infectious Diseases (**Leopoldina**)
- Working Group Post-Infectious Diseases of the German Centers for Health Research (**DZG**), commissioned by German Center for Infection Research (**DZIF**)
- Member of the Expert Group „Long COVID Off-Label-Use“ commissioned by the Federal Health Ministry (**BMG**) in cooperation with the Federal Institute for Drugs and Medical Devices (**BfArM**)
- Guest on Long COVID Round Tables of the Federal Ministry of Health (**BMG**)
- Member of the Corona Task Force of the German Society of Pediatrics in cooperation with the German Society of Pediatric Infectiology (**DGKJ-DGPI**)
- Member of the Scientific Advisory Board Post-COVID-Syndrom of the German Medical Association (**BÄK**)
- (Co)coordination of Long COVID Guidelines of the Association of the Scientific Medical Societies in Germany (**AWMF**)
- Member of the Scientific Advisory Board of the German Society for ME/CFS (**DG ME/CFS**)
- Founding board member of the Long COVID Physicians' Association (**ÄVLC**)
- Founding board member of the Parents' Initiative for Children and Adolescents with ME/CFS (**EI MECFS**)

Funding of Research Projects

- Federal Ministry for Health (BMG), Federal Ministry for Research, Technology and Space (BMFTR)
- Bavarian State Ministry for Health and Care (StMGp), Bavarian Ministry for Science and the Arts (StMWK)
- Innovation Fund of the Federal Joint Committee (G-BA)
- People-for-Children Foundation (MKS), Weidenhammer-Zöbele Foundation (WZS), Siemens Foundation Caring Hands, Lost-Voices Foundation (LVS), Auridis Foundation, Leifheit Foundation, Matthias Kurz Foundation, MECFS Research Foundation (MRF)

Honoraria for Lectures

- Bavarian Chamber of Pharmacists (BLAK), District Medical Association of South Württemberg (BÄK SW), Chamber of Pharmacists of Lower Saxony (AKN), Medical District and Regional Association Munich (ÄKBV), Medical Service of Bavaria (MDB), German Academy for the Promotion of Development and Health in Children and Adolescents

€45 million allocated by the BMG for children and adolescents with LC in 2025-2028

NGK4Family

Innovative Project to Support and Develop **Resilience Through Self-help/Self-regulation** for Families of Severely and Very Severely Affected Children and Adolescents with LC and ME/CFS

Soleil Völkl
and NichtGenesenKids e.V.

PedMYCVAC – Follow-up

Prospective Detection of **Vaccine-associated Myocarditis** of Children and Adolescents after Vaccination with mRNA COVID-19 Vaccines

Franziska Seidl, Charité

COVYOUTHdata

Recognizing, Understanding and Managing the Long-term Consequences of COVID-19 in Children and Adolescents **at an Early Stage**

Nina Timmesfeld, Bochum
Ingo Mayer, Köln

PEDNET-LC

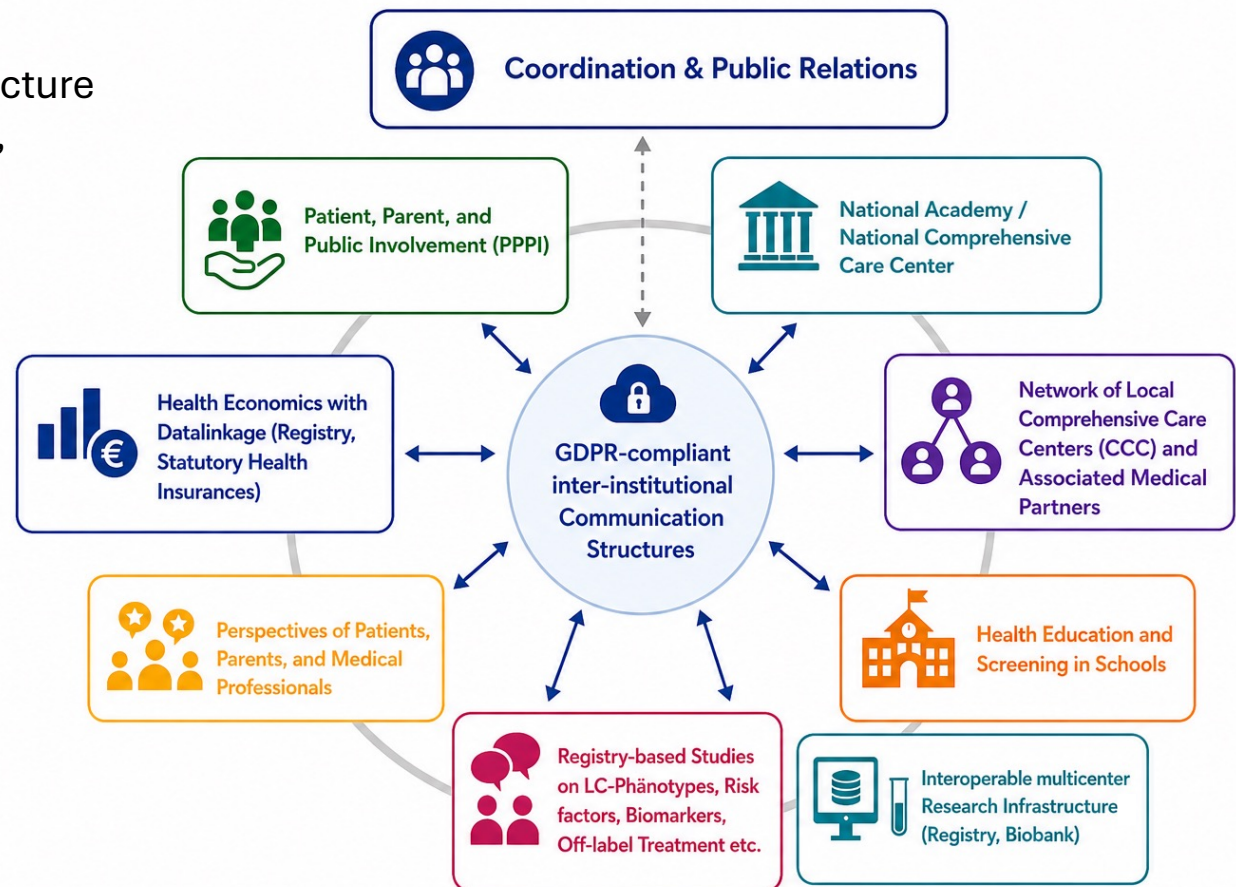
Pediatric Network for Medical Care and Research on Post-acute Sequelae of COVID-19 (PASC), Similar Post-acute Infection and Vaccination Syndromes (PAIVS), and ME/CFS
(41 Mio €)



PEDNET-LC Aims and Work Packages

Use, evaluate, and further develop knowledge, experience, and infrastructure within a nationwide, interdisciplinary, multiprofessional network to establish sustainable, state-of-the-art medical care and research for pediatric LC

... thereby providing a model (“use case”) for jointly addressing complex chronic pediatric diseases with comprehensive expertise



PEDNET-LC Participatory Guidance

- Interdisciplinary, multiprofessional, participatory **Steering Board**
- Joint **Project Office**
- International **Scientific Advisory Board**
- National **Patient Advisory Board**

Pediatricians

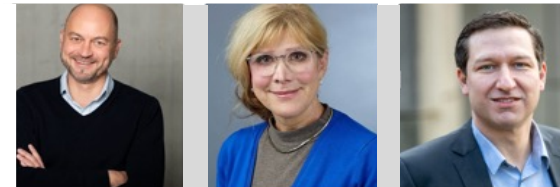


U. Behrends
Munich, TUM

N. Töpfer
Dresden

D. Vilser
Neuburg

Child & Adolescent Psychiatrists

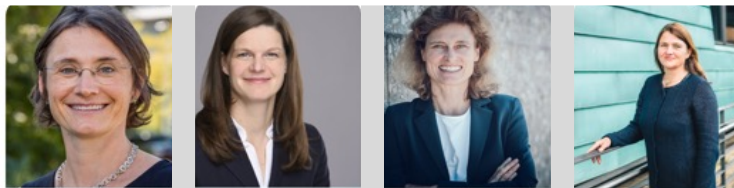


M. Kölch
Rostock

E. Möhler
Homburg

M. Romanos
Würzburg

Healthcare Researchers



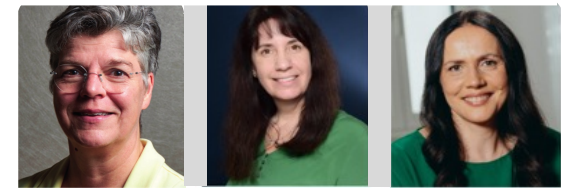
F. De Bock
Berlin

C. Jung-Sievers
Munich, LMU

E. Rehfuess
Munich, LMU

S. Schmidt-Schuchert
Greifswald

Patient & Parent Representatives



C. Ebel
Fatigatio e.V.

S. Englbrecht
EI MECFS e.V.

S. Völkl
NGK e.V.

PEDNET-LC Partners



20 Comprehensive Care Centers (CCC)

[Berlin](#), [Bielefeld](#), [Bremen](#), [Dresden](#), [Essen](#), [Freiburg](#), [Greifswald/Rostock](#), [Hamburg](#), [Homburg](#), [Hannover](#), [Jena](#), [München](#), [Neuburg](#), [Regensburg](#), [Würzburg](#), [Köln](#), [Magdeburg](#), [Worms/Mainz](#), [Kassel](#) und [Lübeck](#)

3 Rehabilitation Clinics

[Bruchweiler](#), [Kreischka](#) und [Wangen](#)

2 Pain Clinics

[Datteln](#) und [Garmisch-Partenkirchen](#)

8 Research Institutes

[Berlin](#), [Dresden](#), [Freiburg](#), [Greifswald/Rostock](#), [Hannover](#), [Marburg](#), [München](#), [Passau](#) und [Regensburg](#)

Joint Biobank

[Dresden](#) und [Freiburg](#)

9 Social Pediatric Centers (SPC)

[Augsburg](#), [Berlin-Neukölln](#), [Dresden](#), [Frankfurt](#), [Memmingen](#), [München](#), [Neuburg](#), [Weiden](#) und [Würzburg](#)

- Health Insurances
- IT Companies
- Professional Associations
- ME/CFS Foundations
- Patient Organizations



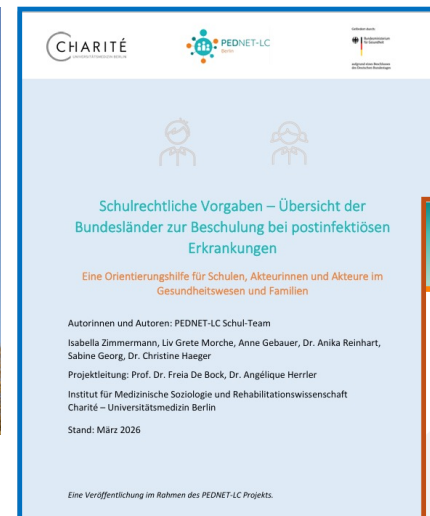
PEDNET-LC Academy

Coordinates ...

- **evidence synthesis**
- **knowledge translation**

Develops products such as ...

- **FAQ sheets**
- **handbooks**
- **SOPs, guidelines**
- **patient education programs**
- **professional training programs**
- **journal and PhD clubs**
- **lectures and workshops**
- **newsletter**
- **publication alert**
- **systematic search strategies**



PEDNET-LC Clinical Network

- Implements ...
 - **standardized, harmonized healthcare for LC** (algorithms, SOPs, guidelines)
- Integrates ...
 - interdisciplinary, multiprofessional diagnostics and therapy in **inpatient and outpatient** settings
 - exemplary telemonitoring, social medical, and palliative care in **home-based settings**
- Discusses ...
 - individual cases **weekly** with a **National Expert Board**
 - teaching cases and updates in **weekly plenary meetings**
- Connects via ...
 - a **data-protection-compliant messaging platform** (Netsfere)
 - interoperable **virtual clinical data hub** (linked to the registry)



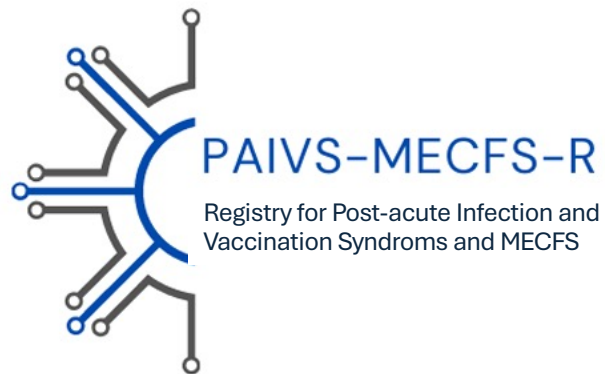
Federal Minister **Nina Warken** and Saxon State Minister **Petra Köpping** visited the PEDNET-LC CCC Dresden



Dresden, March 13th 2026

PEDNET-LC Research Infrastructures

- **PAIVS-MECFS Registry:** longitudinal collection of **complex, standardized, harmonized routine data**
- **PAIVS-MECFS Biobanking Study:** longitudinal collection of **fluid and dry biospecimens** (blood, hair, urine, swabs)




Universitätsklinikum
Carl Gustav Carus
DIE DRESDNER.



PEDNET-LC Studies



Registry Data Analyses

- e.g., Risk Factors, Symptom Clusters, Laboratory Data, Functional Tests, Imaging, Self-management, Healthcare Utilization, Treatments, Disease Trajectories, HRQoL



+



Linked Registry & Healthcare Insurance Data Analyses

- BARMER, AOK Bavaria



+



Registry-based Prospective Clinical and Evaluation Studies

- Diagnostics (Sleep Lab, cMRT)
- Intervention (Dyspnoe - Pulmonary Rehabilitation)
- Patient Perspectives (mixed methods)



+



Registry-based Translational Studies

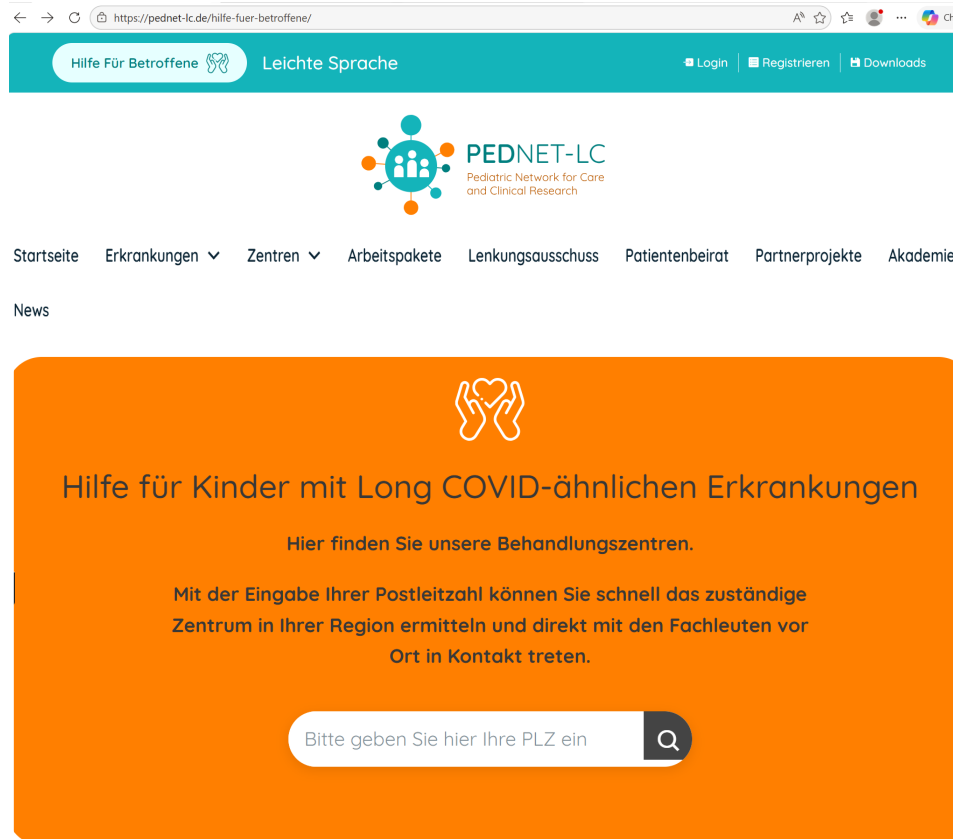
e.g., Genetics



Evaluation Studies

- Perspectives of Primary and Secondary Healthcare Providers
- Perspectives and Knowledge of School Personnel pre/post educational Intervention

PEDNET-LC Information



PEDNET-LC Website <https://pednet-lc.de>

- **provides** public **information** on
 - Long COVID-like diseases (LC)
 - PEDNET-LC activities
 - LC news
- **directs** patients and medical professionals by **postal code** to local CCCs
- **facilitates** internal **knowledge sharing** (private: manuals, talks, SOPs etc.)

PEDNET-LC Synergies

Federal Ministry of Health

Platform for integrated Long-COVID Care And Research (LongCARE)

Ressortforschung im Handlungsfeld „Gesundheitsversorgung“; Querschnittsthema „Long-/Post-COVID“; Förderschwerpunkt „Erforschung und Stärkung einer bedarfsgerechten Versorgung rund um die Langzeitfolgen von COVID-19 (Long COVID)“



G-BA Innovation Fond



KidsCarePVS



Invitation to
Patient Survey:
0-20 years with
PAIS, ME/CFS

kidscarepvs@med.ovgu.de

Federal Ministry of Research, Technology and Space



DEUTSCHE ZENTREN DER
GESUNDHEITSFORSCHUNG



Federal States



Über uns Presse

Krankheitsbilder Informationen für... Versorgungsangebot

Verbesserung der
Versorgung von Kindern
und Jugendlichen mit
Long-COVID in BW



PEDNET-LC Outlook

Nationale Dekade gegen Postinfektiöse Erkrankungen

Gegen postinfektiöse Erkrankungen wie Long COVID oder ME/CFS fehlen bislang wirksame Behandlungsmöglichkeiten. Die Nationale Dekade gegen Postinfektiöse Erkrankungen entschlüsselt Ursachen und Mechanismen und schafft Stück für Stück die Basis zur Entwicklung neuer Therapieoptionen.



 European Commission

EU Funding & Tenders Portal

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Advancing research on the prevention, diagnosis, and management of post-infection long-term conditions

HORIZON-HLTH-2026-01-DISEASE-03

Acknowledgment

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PEDNET-LC Scientific Advisory Board: **D. Buonsenso** (IP4C, Rom, Italien), **J. Hauer** (München), **K. Hoffman** (Wien, Österreich), **L.A. Jason** (Chicago, USA), **D. Nadal** (Zürich, Schweiz), **U. Ravens-Sieberer** (Hamburg, NUM CoverChild), **R. Rowe** (Baltimore, USA), **S. Scheibenbogen** (Berlin Charité, NKSG), **A. Scherrer** (Zürich, Schweiz), **G. Schmidt** (München, AKEK)

*Special thanks to the **PEDNET-LC Patient Advisory Board** as well as to all **patients and parents** supporting PEDNET-LC and related projects !*

