

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

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



Conflict of Interests

Committee Work

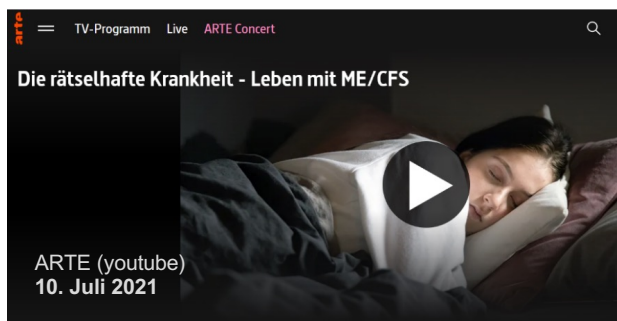
- Expert group „Long COVID Off-Label-Use“ of the Federal Institute for Drugs and Medical Devices (BfArM)
- Round tables „Long COVID“ and „Long COVID Kids“ of the Federal Ministry of Health (BMG)
- Corona task force of the German Society for Pediatrics (DGKJ)
in cooperation with the German Society for Pediatric Infectiology (DGPI)
- Scientific advisory board „Post-COVID Syndrome“ of the der Federal Medical Association (BÄK)
- Coauthor / coordinator of AWMF guidelines ad Long/Post-COVID
- Scientific advisory board of the German Association for ME/CFS (DG ME/CFS)
- Foundation board member of the Physician's Association Long COVID (Ärzte und Ärztinnenverband Long COVID)
- Foundation board member of the Parents' Initiative for Children and Adolescents with ME/CFS Munich (EI ME/CFS)

Funding for Research Projects

- Federal Ministry of Education and Research (BMBF), Federal Ministry of Health (BMG)
- Bavarian State Ministry of Health, Care and Prevention (StMGp), Bavarian State Ministry of Science and Art (StMWK)
- People for Children Foundation (MKS), Weidenhammer Zoebele Foundation (WZS), Siemens Foundation Caring Hands, Lost Voices Foundation (LVS), Auridis Foundation, Leifheit Foundation, Matthias Kurz Foundation, Child and Youth Foundation of the Sparkasse Munich, MECFS Research Foundation (MRF)

Based on Pre-pandemic International Data, in Germany, the Independent IQWiG Estimated up to 90,000 (of 9 Million) School-aged Young People with ME/CFS¹

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¹ Institute for Quality and Efficiency in Health Care (IQWiG), 2023:

https://www.iqwig.de/download/n21-01_me-cfs-aktueller-kenntnisstand_abschlussbericht_v1-0.pdf

UK (age 11-16 years; NICE 2007): **0.98 %** (95 %-KI: [0.65; 1.41]) (Crawley 2011)

USA (age 5-17 years; Fukuda 1994, Jason 2006, IOM 2015): **0.75 %** (95 %-KI: [0.54; 0.96]) (Jason 2020)



Long COVID SOS

The German Federal Ministry of Health (BMG) Announced Public Funding for Projects Addressing Long COVID and Long-COVID-like Diseases in Young People



- **Significant number** of children and adolescents affected
- **High risk** due to age-specific vulnerabilities and psychosocial needs
- **Significant impact** of young people's health on well-being of the society
- **Lack of** specialized healthcare and research structures



Richtlinie

des Gemeinsamen Bundesausschusses
über eine berufsgruppenübergreifende,
koordinierte und strukturierte Versorgung für
Versicherte mit **Verdacht auf Long COVID** und
Erkrankungen, die auf eine **ähnliche Ursache**
oder **Krankheitsausprägung** aufweisen
(Long-COVID-Richtlinie/LongCOV-RL)

in der Fassung vom 21. Dezember 2023
veröffentlicht im Bundesanzeiger (Banz AT 08.05.2024 B1)
in Kraft getreten am 9. Mai 2024



Öffentliche Förderrichtlinie des Bundesministeriums für Gesund- heit (BMG) zum Thema

„Modellmaßnahmen zur Versorgung von Kindern und Jugend-
lichen mit Long COVID und Erkrankungen, die eine ähnliche
Ursache oder Krankheitsausprägung aufweisen“

veröffentlicht am 25.07.2024
auf www.service.bund.de

Four „Model Measures for the Care of Children and Adolescents with Long COVID and Diseases with a Similar Cause or Manifestation” Have Been Granted, 45 Mio €

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 Vökl
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, Chaité

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 of post-acute sequelae of COVID-19 (PASC), similar post-acute infection and vaccination syndromes (PAIVS) and ME/CFS
(41 Mio €)



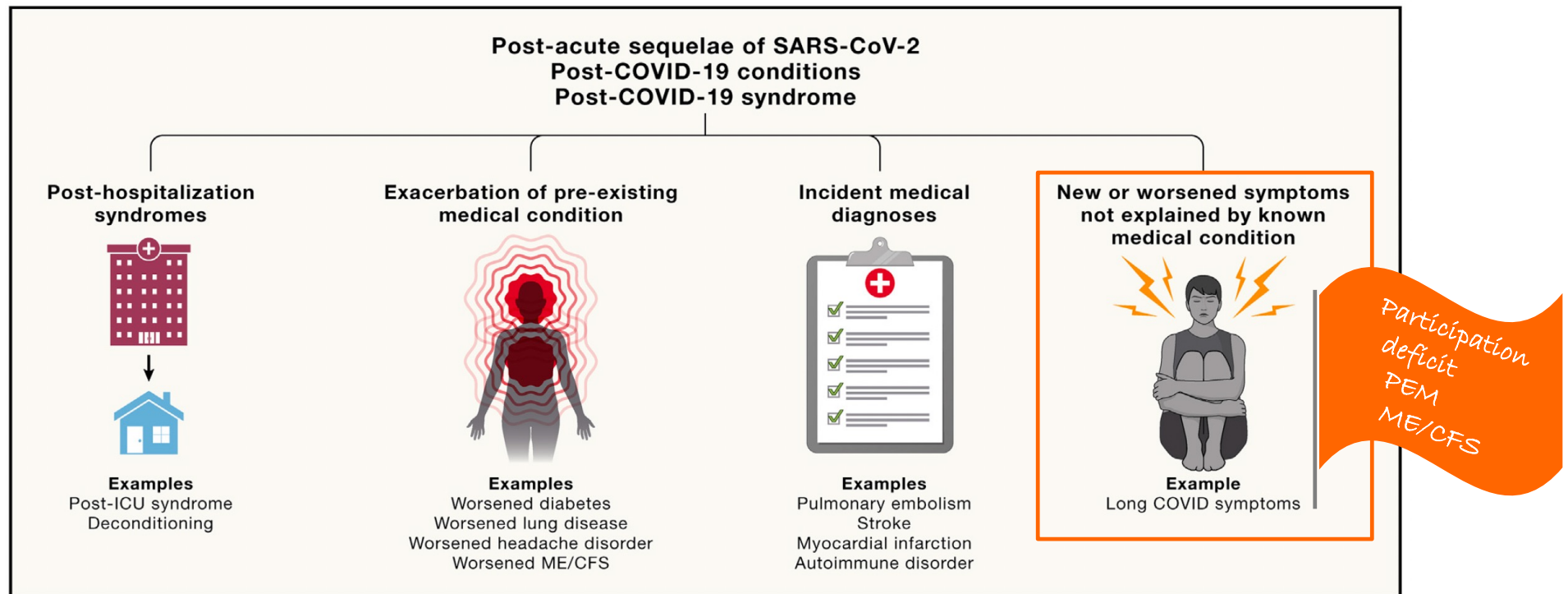
PEDNET-LC

PEDNET-LC will use, evaluate and further develop knowledge, experience, and infrastructure to establish sustainable, state-of-the-art care & research for Long COVID-like diseases (LC) in adolescents and children



- **20** Interdisciplinary „Comprehensive Care Center for LC“ (**CCC-LC**)
- **2** Pediatric Pain Clinics
- **3** Pediatric Rehabilitation Clinics
- **8** Research Institutes (Medical Informatics, Health Services Research)
- Health Insurances (Barmer, AOK BY, AOK NO)
Professional Associations, Patient Organizations,
ME/CFS Foundations

Focus on Complex LC with Participation Deficit, PEM and/or ME/CFS



Peluso MJ, Deeks SG. Cell. 2024 (orange adapted)

Work packages



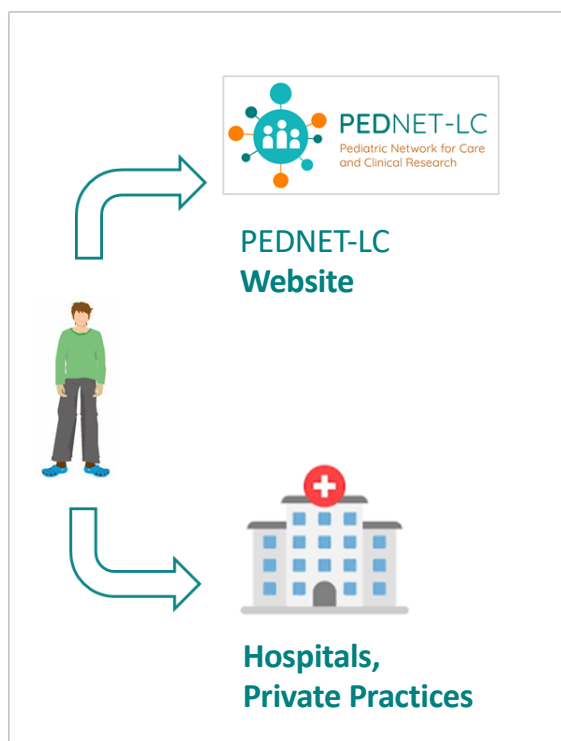
PEDNET-LC

- 1 **Multi-disciplinary/professional Project Steering:** Coordination, Networking, Public Relations, Map of Services *et al.*
- 2 **Participation:** Patient, Parent, and Public Involvement (PPPI)
- 3 **National CCC-LC:** Evidence Research, Knowledge Translation (e.g.SOPs, Guidelines, Education Programs), Expert Board
- 4 **Federal CCC-LCs:** Tertiary Centers, SPZ, Telemedicine, SAPV-KJ, SMN, Education Programs, Federal Expert Boards
- 5 **School:** Education of School Staff, Screening for LC, Evaluation
- 6 **Telemedical Infrastructures:** Cross- and Intra-sectoral medical communication (PädExpert®, telemessenger)
- 7 **Research Infrastructures:** Clinical Trial Office, REDCap Screening CRF, Registry, Biobank
- 8 **Registry-based Studies:** Analyses of Routine Data, Patient Perspectives, Lung Function, Sleep, cMRI, Genetics
- 9 **Perspectives of Healthcare Providers:** Surveys, Interviews, Workshops
- 10 **Health Economic Analyses:** Linkage of Registry Data & Health Insurance Data

CRF: Clinical Report Forms, **FAQ:** Frequently Asked Questions, **SOPs:** Standard Operating Procedures,
SPZ: Social Pediatric Centers, **SAPV-KJ:** Specialized Outpatient Palliative Care for Children and Young People, **SMN:** Social-Medical Follow-up Care (Bunte Kreise)



Patient Recruitment, Screening, and Admission to CCC-LC



Patients get **E-Mail contact** from the responsible **Federal CCC-LC** depending on their **ZIP Code**

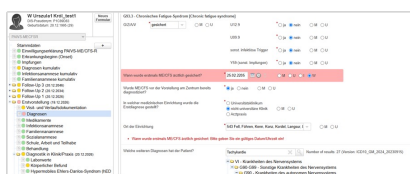




Mother Registries, PAIVS-MECFS Registry and PAIVS-MECFS Biobank

PAIVS-MECFS-Registry

- Supports collection of standardized, harmonized routine data
- Integrates patient-reported data from REDCap CRF
- Collects multiple data from medical visits
- Provides a large dataset for registry-based studies
- Includes data from patients with a) all types of LC or b) with similar symptoms, but differential diagnosis



PAIVS-MECFS-Biobank



MECFS Registry



Article

The German Multicenter Registry for ME/CFS (MECFS-R)

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<https://doi.org/10.1007/s00431-023-05351-z>

Multicenter Long Covid Registry (MLCR)

RESEARCH



Pediatric and adult patients with ME/CFS following COVID-19: A structured approach to diagnosis using the Munich Berlin Symptom Questionnaire (MBSQ)

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Bayerisches Staatsministerium für
 Gesundheit, Pflege und Prävention



Kick-Off May 06 2025 in Berlin



Berlin, May 12 2025

MECFS Conference, PEDNET-LC, Behrends

Thanks to the Steering Committee, Partners, and Scientific Advisory Board



PEDNET-LC

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Thank you for Your Attention !