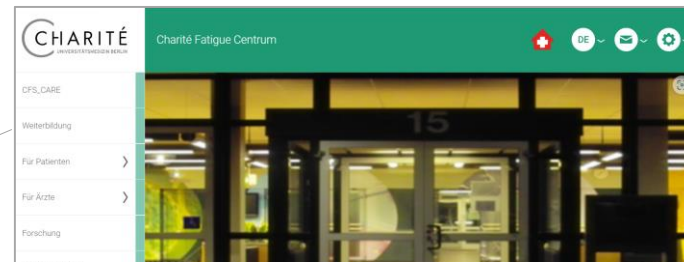
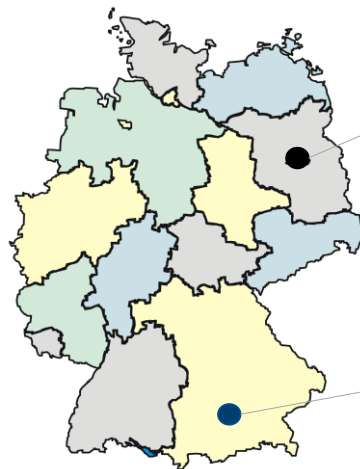


# Diagnosing ME/CFS – State of the Art

**Uta Behrends**

**MRI Chronic Fatigue Center for Young People (MCFC)**  
Children's Hospital, Technical University Munich (TUM)  
and Munich Municipal Hospital (mük)

<https://www.mri.tum.de/chronische-fatigue-centrum-fuer-junge-menschen-mcfc>  
[mcfc.kinderklinik@mri.tum.de](mailto:mcfc.kinderklinik@mri.tum.de)



## Committee Work

- Corona Task Force, German Associations of Pediatrics (DGKJ) and Pediatric Infectiology (DGPI)
- Scientific Advisory Board „Post-COVID-Syndrom“, Federal Medical Association (BÄK)
- Author Group, AWMF Guideline Long/Post-COVID
- Board Foundation Member, Medical Association Long COVID
- Medical Advisory Board, German Association for ME/CFS
- Board Foundation Member, „Elterninitiative ME/CFS-krankte Kinder & Jugendliche e.V.“

## Research Grants

- Federal Ministry of Education and Research (BMBF)
- Federal Ministry of Health (BMG)
- Bavarian Ministry of Health and Care (StMGP)
- Bavarian Ministry of Science and Arts (StMWK)
- German Center for Infection Research (DZIF)
- People for Children (Menschen für Kinder) Foundation
- Weidenhammer-Zöbele Foundation
- Lost-Voices Foundation

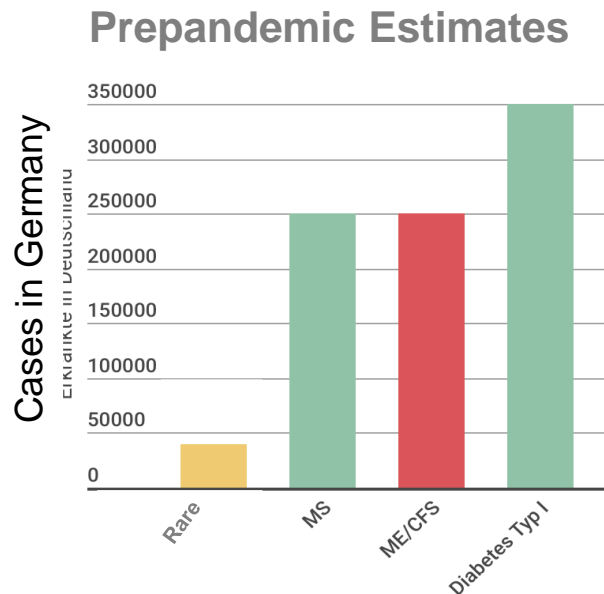
## Travel Grants, Lecture Fees

- Weidenhammer-Zöbele Foundation
- Bavarian Association of Pharmacists (BLAK)
- German Association of Pediatric Rehabilitation

# ME/CFS is Not Rare

- ME/CFS is affecting **millions of people** world-wide, with **increasing prevalence** due to the COVID-19 pandemic

Rössler M. PLoS Med. 2022



© German Society for ME/CFS



## ÖFFENTLICHE ANHÖRUNG IM AUSSCHUSS FÜR GESUNDHEIT DES DT. BUNDESTAGES AM 19. APRIL 2023

STELLUNGNAHME DER KBV ZUM ANTRAG DER CDU/CSU-  
BUNDESTAGSFRAKTION „ME/CFS-BETROFFENEN SOWIE DEREN  
ANGEHÖRIGEN HELFEN – FÜR EINE BESSERE GESUNDHEITS- SOWIE  
THERAPIEVERSORGUNG, AUFKLÄRUNG UND ANERKENNUNG“  
(BT-DRS.: 20/4886 VOM 14. DEZEMBER 2022)

Cases 2018 /2019: **350.000 - 400.000**

Cases 2021: almost **500.000**

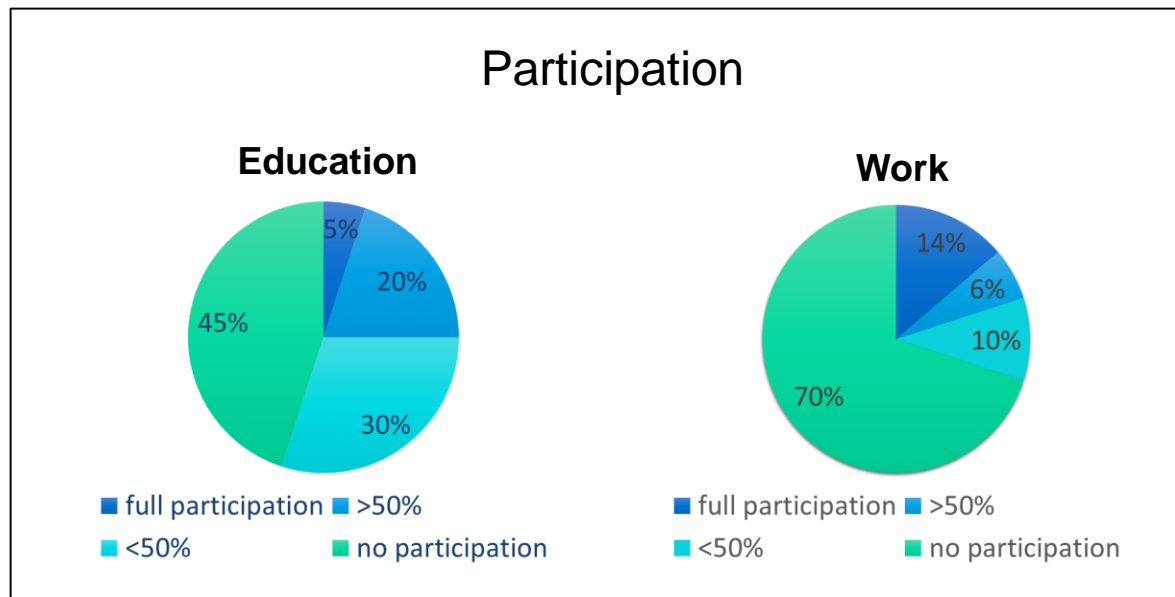
National Association of Statutory Health Insurance Physicians (KVB):  
Statement for Hearing in the German Bundestag 19.4.2023

- Pre-pandemic U.S. studies indicated that **84%–91%** of ME/CFS patients might be undiagnosed

Jason et al., Child Youth Care Forum. 2020 and ref. therein

# ME/CFS is Complex and Disabling

- **25 %** mild, **50%** moderate **25 %** severe cases (home- or bedbound)
- **60 %** not able to work
- Most frequent course of **long-term school absence**
- **Lower quality of life** than with other severe chronic diseases (e.g. cystic fibrosis, multiple sclerosis)
- **Disease sequelae** include social isolation, depression, and suicidality



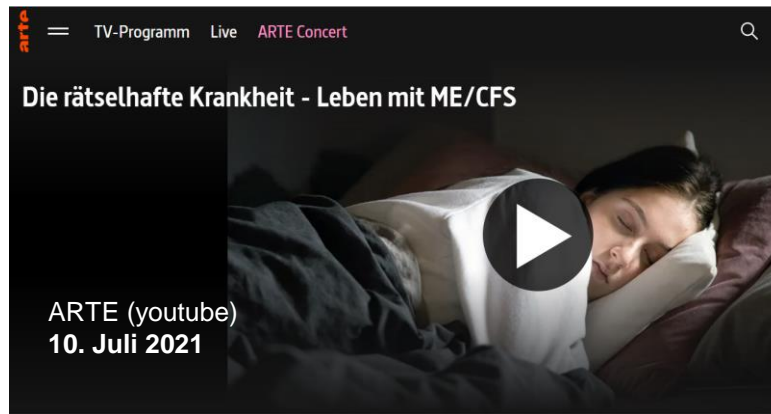
See poster Hieber H et al. (n=174)

Fröhlich L, J Health Psychol. 2022  
Rowe PC, Front Pediatr 2017  
Rowe KS, Front Pediatr 2019  
McManimen SL, Fatigue. 2016

Centers for Disease Control and Prevention (CDC) 2021  
National Institute for Health and Care Excellence (NICE) 2021

# Diagnosing ME/CFS can be Challenging

1. No confirming **biomarker** established → no gold standard
2. Symptoms are **common** to many illnesses
3. Symptoms can **vary** over time
4. At medical visits patients may **not obviously** appear ill
5. Severely affected may be **too ill** to seek care
6. **Communication** challenges (age, symptoms, prior health care experiences)
7. **Education** about and **acceptance** of the disease might be limited



# A Timely “State-of the-Art” Diagnosis ....

... can be established by

- **a comprehensive medical history**
- **evaluating clinical ME/CFS criteria**
- **thorough physical examination**
- **targeted differential diagnostics**
- **identification of comorbidities.**



**Prioritize all diagnostic steps !**

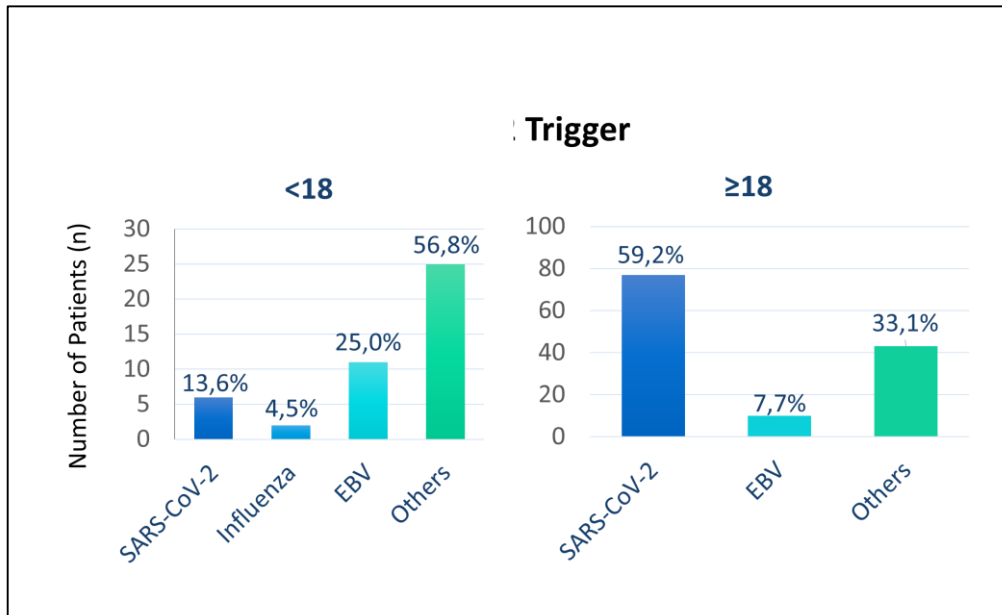
... is essential to

- **offer timely care**
  - reduce symptom load
  - prevent symptom worsening
  - prevent disease sequelae
- **improve prognosis**
- **reduce socioeconomic impact**
- **generate reliable epidemiological data**



# Medical History (1) - Trigger

- e.g. infection, vaccination, trauma, surgery



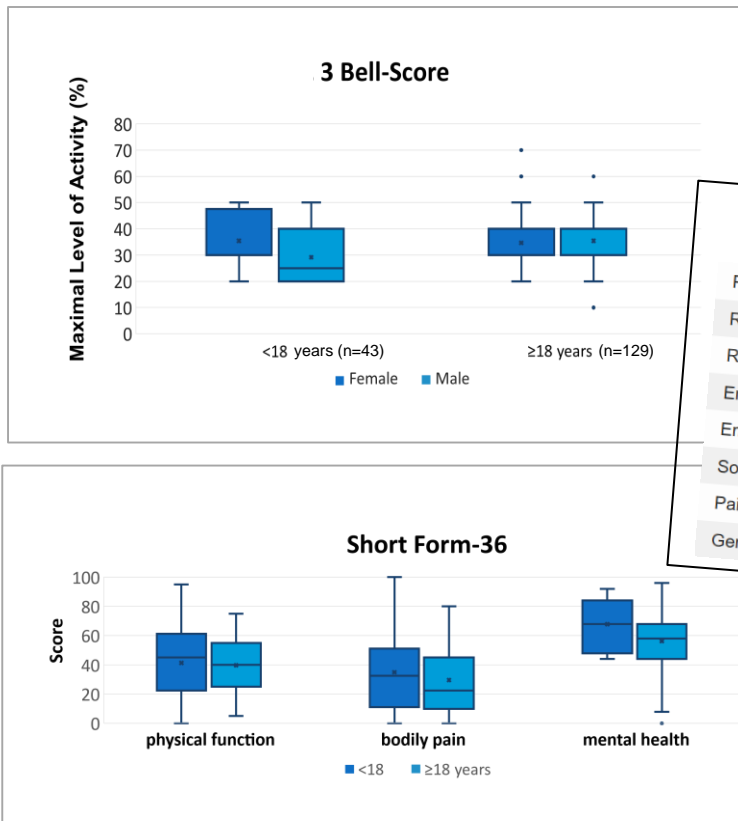
See poster Hieber H et al. (n=174)

Post-COVID condition **ICD-10 U09.9!**  
After 3 (adults), 2 (children & adolescents) months



# Medical History (1) - Level of Activity / Disability

**Significant reduction or impairment of the ability to engage in educational, social, or personal activities that were usual before the illness**



See poster Hieber H et al. (n=174)

## Bell's CFIDS Disability Scale

**100:** No symptoms at rest; no symptoms with exercise; ...

**90:** No symptoms at rest; mild symptoms with activity; ...

**80:** Mild symptoms at rest; symptoms worsened by exercise;....

**70:** Mild symptoms at rest; some daily activity limitation clearly noted. ... Able to work full-time with difficulty.

**60:** Mild to moderate symptoms at rest; daily activity limitation clearly noted. ... Unable to work full-time in jobs requiring physical labor, but able to work full-time in light activity if hours flexible.

**50:** Moderate symptoms at rest. ... Unable to perform strenuous duties, but able to perform light duty or desk work **4-5 hours a day**, but requires rest periods.

**40:** Moderate symptoms at rest. ... Not confined to house. Unable to perform strenuous duties; able to perform light duty or desk work **3-4 hours a day**, but requires rest periods.

**30:** Moderate to severe symptoms at rest. Severe symptoms with any exercise; overall activity level reduced to 50% of expected. Usually confined to house. Unable to perform any strenuous tasks. Able to perform desk work **2-3 hours a day**, but requires rest periods.

**20:** Moderate to severe symptoms at rest. Unable to perform strenuous activity; overall activity 30%-50% of expected. **Unable to leave house except rarely**; confined to bed most of day; unable to concentrate for more than 1 hour a day.

**10:** Severe symptoms at rest; bedridden the majority of the time. **No travel outside of the house**.

Marked cognitive preventing concentration.

**0:** Severe symptoms on a continuous basis; **bedridden constantly; unable to care for self**.

## SF-36

Physical functioning

Role limitations due to physical health

Role limitations due to emotional problems

Energy/fatigue

Emotional well-being

Social functioning

Pain

General health



# Medical History (2) – Core Symptoms

**Symptoms are of at least moderate severity and present at least 50% of the time !**

**PEM is a mandatory diagnostic criterion !**

1. **Fatigue** for  $\geq 6$  (3) months which is of new onset, not explained by ongoing or unusual excessive exertion, not relieved by rest, and preventing pre-illness level of activity
2. **Post-exertional malaise (PEM)**, a worsening of symptoms after physical or mental activities that were well-tolerated before, often 12 to 48 hours after activity and lasting for days or even weeks (“crash”, “collapse”)
3. **Sleep disturbance**, “unrefreshing” sleep, problems falling/staying asleep, day-night rhythm impaired
4. **Neurocognitive impairment** (“brain fog”), slow thinking, memory and attention deficits hypersensitivity to light, noise, or touch
5. **Orthostatic intolerance**
6. **Pain**, including headaches, muscle/joint pain without swelling or redness
7. **Weight loss, temperature dysregulation**
8. **Flu-like symptoms**, new allergies

Institute of Medicine (**IOM**) “Systemic Exertion Intolerance Disease” (**SEID**), U.S (National Academies Press (US); 2015).

Centers of Disease Control and Prevention (**CDC**), U.S (<https://www.cdc.gov>)

National Institute of Health and Care Excellence (**NICE**), U.K (<https://www.nice.org.uk/guidance/ng206>)

European Network on ME/CFS (**EUROMENE**), Europe (Nacul L, Medicina 2021)

German Association of General Medicine (**DEGAM**), D 2022

([https://register.awmf.org/assets/guidelines/053-002I\\_S3\\_Muedigkeit\\_2023-01\\_01.pdf](https://register.awmf.org/assets/guidelines/053-002I_S3_Muedigkeit_2023-01_01.pdf))

# Algorithm to Evaluate Diagnostic Criteria

**MRI TUT**  
Klinikum rechts der Isar Technische Universität München

**CHARITÉ**  
UNIVERSITÄT MEDIZINISCHES KOLLEGE

**Munich Berlin Symptom Questionnaire (MBSQ) – Ärztliche Anamnesebogen für Kinder und Jugendliche bei Verdacht auf Myalgische Enzephalomyelitis/Chronisches Fatigue-Syndrom (ME/CFS)**

Name: \_\_\_\_\_ Vorname: \_\_\_\_\_ Name (Ärzt\*in): \_\_\_\_\_  
Geburtsdatum: \_\_\_\_\_ Datum (Ärzt\*in): \_\_\_\_\_  
Ausfüller: \_\_\_\_\_ min \_\_\_\_\_ Einrichtung: \_\_\_\_\_

Dieser Bogen stellt die Grundlage für ein **ärztliches Gespräch** dar. **Offene Punkte oder Verständnisprobleme** müssen im ärztlichen Gespräch geklärt werden. ME/CFS ist eine Ausschlussdiagnose. Aus dem alleinigen Ausfüllen dieses Fragebogens kann **keine Diagnose** abgeleitet werden. Die **ärztliche Beurteilung** muss zusammen mit dem Auswertungsbogen erfolgen. Bitte fülle den Fragebogen soweit möglich alleine aus und lass Dir falls nötig von Deinen Eltern helfen.

	Während der letzten 3 Monate				Ärztlicher Vermerk
	Liegt nicht vor	Häufigkeit 1 = manchmal 2 = etwa 1/2 der Zeit 3 = meistens 4 = immer	Schwere 1 = mild 2 = moderat 3 = schwer 4 = sehr schwer		
<b>I Fatigue/ Alltagsfunktion</b>					
1 Fatigue (Erschöpfung, Abgeschlagenheit, Schläppheit, Schwäche, Mangel an Energie)	0	1 2 3 4	1 2 3 4		
2 Einschränkungen im Alltag – Schule/ Ausbildung	0	1 2 3 4	1 2 3 4		
3 Interaktion mit Familie, Freunden, Freunden, Familie, Tag – Persönlich (Selbst)	0	1 2 3 4	1 2 3 4		
Für zu einem definierten Zeitpunkt begonnen: O Triff zu O Triff nicht zu					
6 Die Fatigue ist nicht Folge von anhaltender, exzessiver Belastung	0	1 2 3 4	1 2 3 4		
7 Die Fatigue bessert sich deutlich durch Ausruhen	0	1 2 3 4	1 2 3 4		
<b>II Belastungsabhängige/ belastungsinduzierte Symptomverschärfung</b>					
8 Vermindertes geistiges oder körperliches Durchhaltevermögen	0	1 2 3 4	1 2 3 4		
9 Vermehrte Beschwerden nach alltäglichen Aktivitäten	0	1 2 3 4	1 2 3 4		
Falls Belastungsverschärfung vorliegt:					
12 Welche drei Symptome verschlechtern sich nach alltäglichen Aktivitäten?	1.				
	2.				
	3.				
<b>III Schlaf</b>					
13 Schlaf	0	1 2 3 4	1 2 3 4		
14 Schlaf	0	1 2 3 4	1 2 3 4		
15 Schlaf	0	1 2 3 4	1 2 3 4		
16 Schlaf	0	1 2 3 4	1 2 3 4		
<b>IV Schmerzen</b>					
17 Muskelschmerzen, muskelschmerzartiges Gefühl	0	1 2 3 4	1 2 3 4		
18 Gelenkschmerzen ohne Schwellung oder Rötung	0	1 2 3 4	1 2 3 4		
19 Kopfschmerzen	0	1 2 3 4	1 2 3 4		
20 Bauchschmerzen	0	1 2 3 4	1 2 3 4		

Erstellung des Leitensystems PEM empfehlen wir zusätzlich den DSG-PEM zu verwenden. Siehe: Colter J, Holman C, Duden C, Jason LA. A Brief post-Exertional Malaise. Diagnostics (Basel). 2018;8(3):66. Published 2018 Sep 11. Doi: 10.3390/diagnostics8030066. Eine deutsche Version kann bei [www.mbsq.de](https://www.mbsq.de) heruntergeladen werden.

1 Fatigue

2 Post-Exertional Malaise PEM

3 Sleep Dysregulation

4 Pain

	Während der letzten 3 Monate				Ärztlicher Vermerk
	Liegt nicht vor	Häufigkeit 1 = manchmal 2 = etwa 1/2 der Zeit 3 = meistens 4 = immer	Schwere 1 = mild 2 = moderat 3 = schwer 4 = sehr schwer		
<b>V Neurokognitive Manifestationen</b>					
27 Konzentrationsschwierigkeiten	0	1 2 3 4	1 2 3 4		
28 Wortfindungsstörungen	0	1 2 3 4	1 2 3 4		
29 Falls kognitive Beschwerden (Nr. 27-28) vorliegen, verschlechtern sich diese durch Anstrengung/ Stress oder Zeitdruck?	Ja	Nein			
30 Gedächtnisverlust	0	1 2 3 4	1 2 3 4		
31 Schwierigkeiten, Informationen abzurufen	0	1 2 3 4	1 2 3 4		
32 Mangelnde Multitaskingfähigkeit	0	1 2 3 4	1 2 3 4		
33 Schwierigkeiten beim Ausdrücken v. Gedanken	0	1 2 3 4	1 2 3 4		
34 Beim Denken oft den Faden verlieren	0	1 2 3 4	1 2 3 4		
35 Neue Schulprobleme (z.B. in Mathematik)	0	1 2 3 4	1 2 3 4		
36 Wahrnehmung-, Empfindungs- und/oder Sinnesstörungen (z.B. verschwommenes Sehen)	0	1 2 3 4	1 2 3 4		
37 Koordinations-/Schwergleichheiten	0	1 2 3 4	1 2 3 4		
38 Muskelzuckungen	0	1 2 3 4	1 2 3 4		
39 Muskelschwäche	0	1 2 3 4	1 2 3 4		
40 Lichtempfindlichkeit	0	1 2 3 4	1 2 3 4		
41 Geräuschempfindlichkeit	0	1 2 3 4	1 2 3 4		
42 Berührungsempfindlichkeit	0	1 2 3 4	1 2 3 4		
43 Überlastung durch positive und/oder negative Emotionen	0	1 2 3 4	1 2 3 4		
<b>VI Autonome Manifestationen</b>					
44 Schwindel/ Benommenheit	0	1 2 3 4	1 2 3 4		
45 Muskelschmerzen/ Muskelschwäche	0	1 2 3 4	1 2 3 4		
46 Schwindel/ Benommenheit	0	1 2 3 4	1 2 3 4		
47 Schwindel/ Benommenheit	0	1 2 3 4	1 2 3 4		
48 Schwindel/ Benommenheit	0	1 2 3 4	1 2 3 4		
51 Belastungsabhängige Atembeschwerden	0	1 2 3 4	1 2 3 4		
<b>VII Neuroendokrine Manifestationen</b>					
52 Temperaturinstabilitäten (z.B. angedeckte Hände)	0	1 2 3 4	1 2 3 4		
<b>VIII Immunologische Manifestationen</b>					
53 Infektionskrankheiten (z.B. Grippe, Infektionen)	0	1 2 3 4	1 2 3 4		
54 Infektionskrankheiten (z.B. Grippe, Infektionen)	0	1 2 3 4	1 2 3 4		
55 Infektionskrankheiten (z.B. Grippe, Infektionen)	0	1 2 3 4	1 2 3 4		
56 Infektionskrankheiten (z.B. Grippe, Infektionen)	0	1 2 3 4	1 2 3 4		
<b>Sonstige Fragen zum Symptomenverlauf</b>					
Falls Beschwerden vorliegen, was sind die drei Hauptbeschwerden dieses Fragebogens?	1.				
	2.				
	3.				

Munich Berlin Symptom Questionnaire (MBSQ), Version 3.0 von 28.03.2022, erstellt von K. Wiehler, J. Paulick, R. Piroos, A. Leone, C. Scheibebogen, U. Behr

5 Neurocognitive Dysfunction

6 Autonomous Dysfunction

7 Neuroendocrine Dysfunction

8 Immunological Dysfunction

## SEID/IOM Criteria

- Major Criteria 1-3: **3/3**
- Minor Criteria 5,6: **1/2**

## Canadian Consensus Criteria (CCC)

- Major Criteria 1-5: **5/5**
- Minor Criteria 6-8: **2/3**

No other medical explanation

**CCC**, Carruthers BM, Journal of Chronic Fatigue Syndrome 2003

**SEID / IOM -Kriterien**, Institute of Medicine, National Academy of Sciences 2015

**Pediatric case definition**, Jason LA, Journal of Chronic Fatigue Syndrome 2006

**Pediatric clinical diagnostic worksheet**, Rowe PC, Front Pediatr. 2017

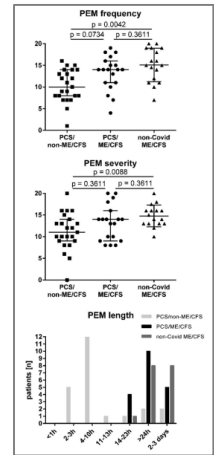
Centers of Disease Control and Prevention (**CDC**), U.S.  
European Network on ME/CFS (**EUROMENE**), Europe

# De Paul Symptom Questionnaire (DSQ) - PEM

## 2 Steps to evaluate PEM

**Question 1-4:** frequency & severity have to be  $\geq 2$  (scale 0-4)  
(*obligatory threshold*)

**Question 6-10:** evaluate physical vs. mental efforts as triggers,  
duration quick vs. hours (*can increase specificity*)



Kedor C, Nature Comm 2022

Symptoms	Frequency: Throughout the <b>past 6 months</b> , <b>how often</b> have you had this symptom? For each symptom listed below, circle a number from:					Severity: Throughout the <b>past 6 months</b> , <b>how much</b> has this symptom bothered you? For each symptom listed below, circle a number from:				
	0 = none of the time	1 = a little of the time	2 = about half the time	3 = most of the time	4 = all of the time	0 = symptom not present	1 = mild	2 = moderate	3 = severe	4 = very severe
1. Dead, heavy feeling after starting to exercise	0	1	2	3	4	0	1	2	3	4
2. Next day soreness or fatigue after non-strenuous, everyday activities	0	1	2	3	4	0	1	2	3	4
3. Mentally tired after the slightest effort	0	1	2	3	4	0	1	2	3	4
4. Minimum exercise makes you physically tired	0	1	2	3	4	0	1	2	3	4
5. Physically drained or sick after mild activity	0	1	2	3	4	0	1	2	3	4

For each question below, choose the answer which best describes your PEM symptoms.

6. If you were to become exhausted after actively participating in extracurricular activities, sports, or outings with friends, would you recover within an hour or two after the activity ended?	Yes	No				
7. Do you experience a worsening of your <b>fatigue/energy related illness</b> after engaging in minimal physical effort?	Yes	No				
8. Do you experience a worsening of your <b>fatigue/energy related illness</b> after engaging in mental effort?	Yes	No				
9. If you feel worse after activities, how long does this last?	≤1 h	2–3 h	4–10 h	11–13 h	14–23 h	≥ 24 h
10. If you do not exercise, is it because exercise makes your symptoms worse?	Yes	No				

Symptom	MS % (n)	ME and CFS % (n)
Quick Recovery	42.3 (66)	1.3 (5)
Exercise Exacerbation	10.8 (17)	47.6 (179)
Physical Exacerbation	65.6 (103)	94.7 (356)
Mental Exacerbation	55.4 (87)	91.4 (342)

Symptom	MS % (n)	ME and CFS % (n)
No Exacerbation	21.0 (33)	2.1 (8)
$\leq 1$ h	10.8 (17)	0.8 (3)
2-3 h	28.7 (45)	2.1 (8)
4-10 h	17.2 (27)	6.1 (23)
11-13 h	3.2 (5)	1.3 (5)
14-23 h	10.2 (16)	14.1 (53)
$\geq 24$ h	8.9 (14)	73.4 (276)

# Additional Questionnaires can be **Helpful** & **Harmful**

... analyse with caution  
by ME/CFS-experienced staff !

... use tools recommended  
for ME/CFS



NIH National Institute of  
Neurological Disorders and Stroke

#### Core Instruments:

- DePaul Symptom Questionnaire (DSQ) **OR** ME/CFS Symptom Checklist

#### Supplemental – Highly Recommended (study focus dependent) Instruments/CRFs:

- Composite Autonomic Symptom Scale
- Child Health Questionnaire
- Sleep Assessment Questionnaire – Moldofsky
- Children's Paced Auditory Serial Addition Task (ChiPASAT)
- Beck Anxiety Inventory (BAI)
- Beck Depression Inventory II (BDI-II)
- Fatigue Severity Scale (FSS)
- Brief Pain Inventory (Short Form) (BPI)
- Revised Fibromyalgia Impact Questionnaire (FIQR)

<https://www.commondataelements.ninds.nih.gov/>

## Patient Health Questionnaire-9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

For office coding: 0 + 0 + 0 + 0 = Total Score 0

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?\*

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

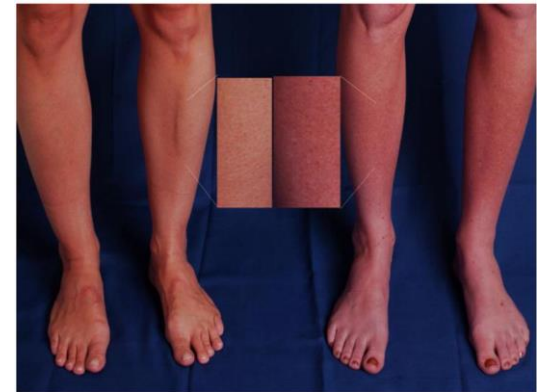
\* This question is not scored

Adapted from the patient health questionnaire (PHQ) screeners ([www.phqscreeners.com](http://www.phqscreeners.com)). Accessed October 6, 2016. See website for additional information and translations.

# Physical Examination

## Physical Exam, e.g.

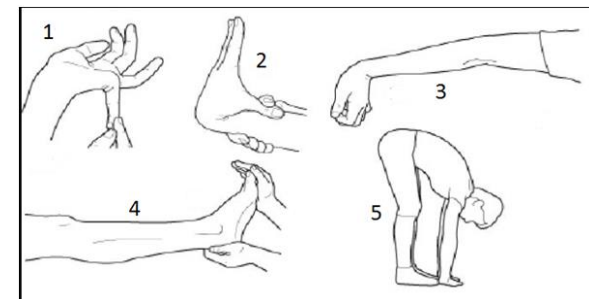
- Facial pallor, swelling
- Suborbital shadow
- Non-exudative pharyngitis
- Palpable, tender cervical and/or axillary lymphnodes
- Muscle tenderness
- Unusually cold hand/feet
- Dependent rubor of legs
- Hypermobility (Beighton score)



Raj SR, Circulation 2013

## Vital signs

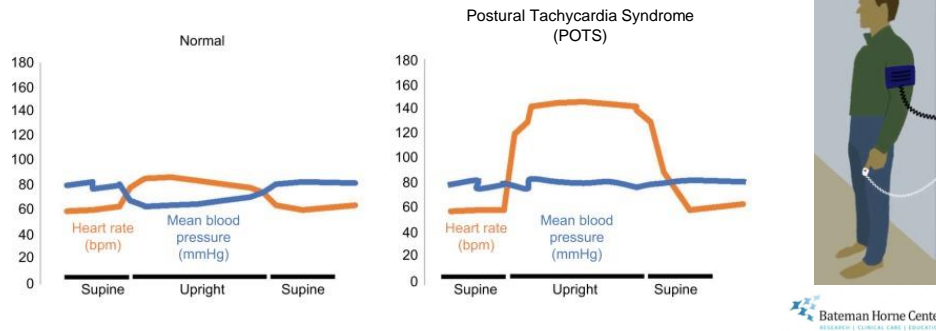
- Increased/ subnormal body temperature
- $\uparrow$  HR  $\downarrow$  RR



<https://www.physio-pedia.com/>

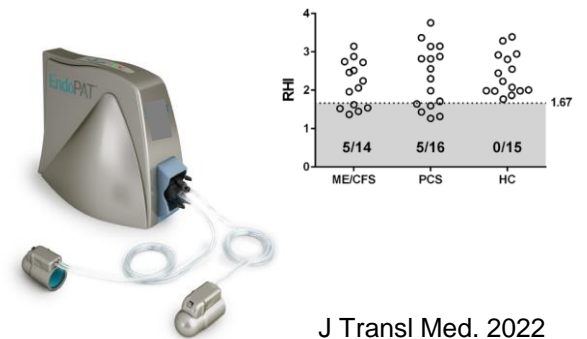
# Functional Tests – Biomarker Puzzle

## Passive 10-Minute Standing Test (NASA Lean Test)



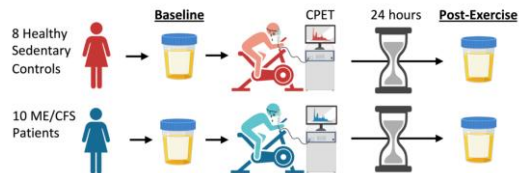
Wells R et al., Vasc Health Risk Manag. 2017

## Endothelial Dysfunction (RH-PAT)



## 2-Day Cardiopulmonary Exercise Testing (CPET)

Not generally applicable,  
impact in biomarker  
research



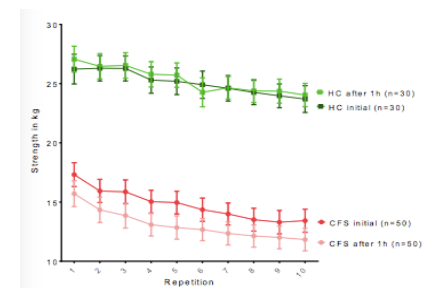
Glass KA, Int J Mol Sci. 2023

## Retinal Microcirculation (OCT-A)



Schlick S, Int J Mol Sci. 2022

## Hand Grip Strength



Jaekel B, J. Transl Med. 2021

# Laboratory Investigations – Biomarker Puzzle

## Routine Lab Investigations

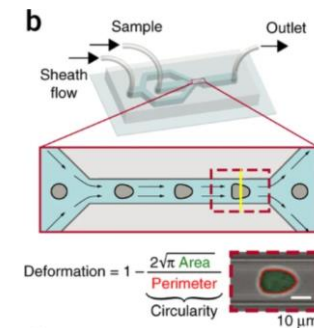
Blood count with differential

- Erythrocyte sedimentation rate
- C-reactive protein
- Anti-nuclear antibodies (**ANA**)
- IgG, IgG, IgM (IgG-subclasses)
- Electrolytes
- Fasting glucose
- Liver function
- Total protein, albumin
- Renal function, urinalysis
- **Thyroid function**
- **Ferritin, vitamin D3, B12, folate**
- **Celiac screening**



## Multiple Biomarker Candidates

### Real-time fluorescence and deformability cytometry



Rosendahl P, Nat Methods. 2018



# Differential Diagnosis & Comorbidities

## Important Differential Diagnoses\*

Rheumatology  
Endocrinology/Gynecology  
Hematology/Oncology  
Infectiology  
Gastroenterology  
Neurology  
Psychiatry

**Collagenoses, Sjögren syndrome, psoriasis arthritis**  
**Hypothyroidism, severe obesity**  
**Tumor fatigue, severe anemia**  
**Chronic hepatitis**  
**Chronic inflammatory bowel disease, endometriosis**  
**Multiple sclerosis, myasthenia gravis, cervical spine instability**  
**Depression, anxiety, psychosomatic disorders ...**

\*if active disease that explains main symptoms

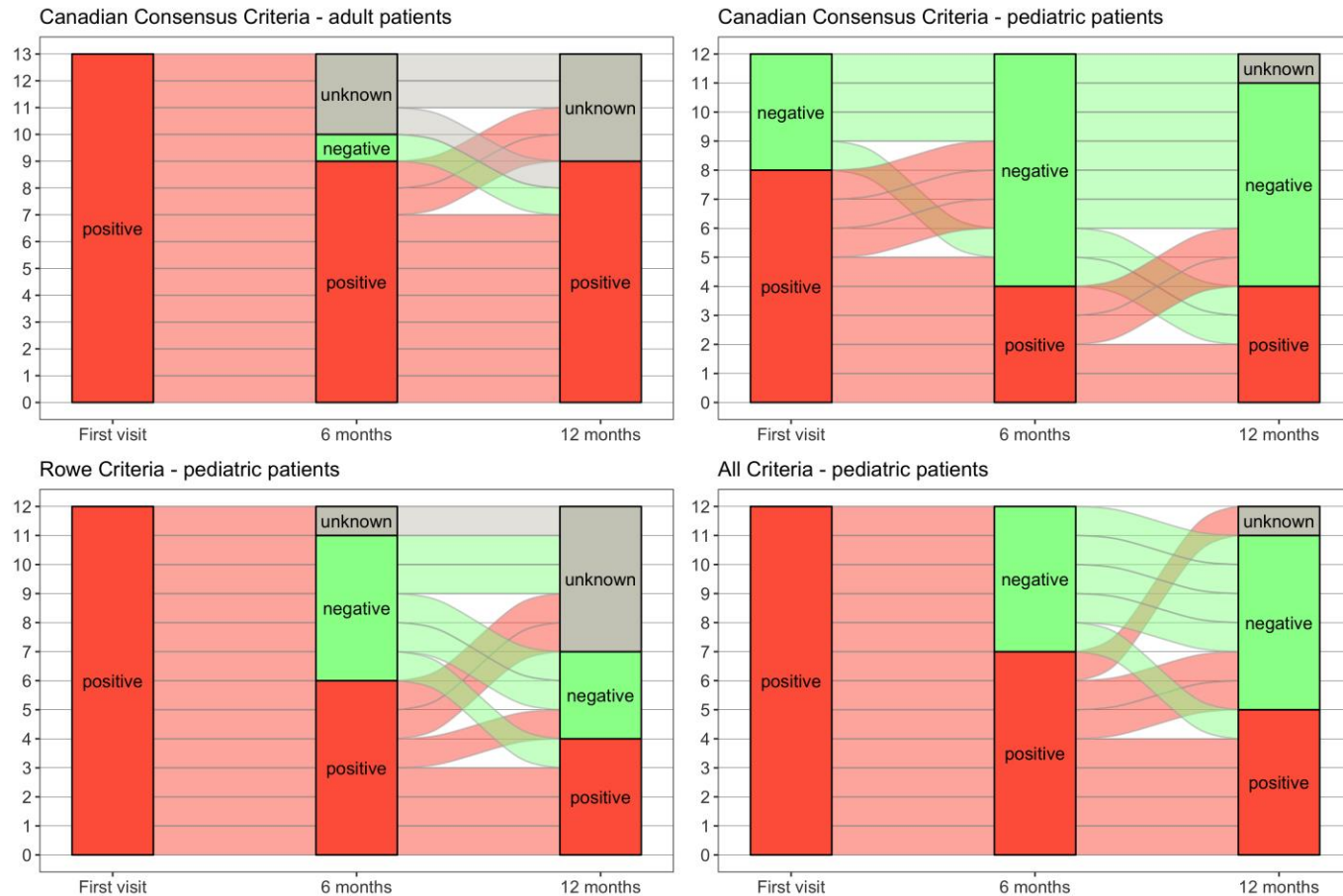
## Frequent Comorbidities

Immunology  
Rheumatology  
Endocrinology/Gynecology  
Gastroenterology  
Neurology/Cardiology

**Immunoglobulin deficiency, mast cell activation syndrome, allergies**  
**Fibromyalgia, sicca syndrome**  
**Hashimoto thyroiditis**  
**Irritable bowel disease, food intolerance**  
**Postural tachycardia syndrome (PoTS), orthostatic hypotension (OH)**  
**sleep apnoea, small fibre neuropathy (SFN), restless legs, migraine**



# Diagnosis of Recovery



Pricoco R, unpublished

Impact of re-evaluation, especially in young people !

# International Classification of Diagnosis (ICD) -10

## Germany

G93.3    Chronisches Fatigue-Syndrom [Chronic fatigue syndrome]  
**Inkl.:** Chronisches Fatigue-Syndrom bei Immundysfunktion  
Myalgische Enzephalomyelitis  
Postvirales (chronisches) Müdigkeitssyndrom

## U.S. - New subcode G93.32

- G93.3**    Postviral and related fatigue syndromes
- **G93.31** Postviral fatigue syndrome
  - **G93.32** Myalgic encephalomyelitis/chronic fatigue syndrome
  - **G93.39** Other post infection and related fatigue syndromes

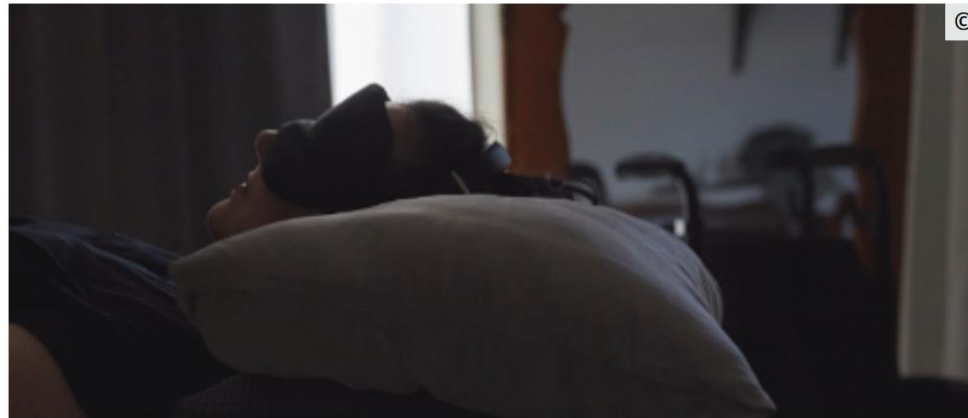
# German ME/CFS Registry



Bundesministerium  
für Gesundheit

**Aufbau eines multizentrischen, altersübergreifenden, klinischen ME/CFS-Registers (MECFS-R) sowie einer multizentrischen, altersübergreifenden ME/CFS-Biobank (MECFS-Bio) mit Auswertung der epidemiologischen, klinischen Versorgungsdaten aus dem MECFS-R**

Ressortforschung im Handlungsfeld „Gesundheitsversorgung“



<https://www.bundesgesundheitsministerium.de/ministerium/ressortforschung/handlungsfelder/gesundheitsversorgung/mecfs.html>

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**LONG COVID**  
DEUTSCHLAND

WEIDENHAMMER  
ZÖBELE **STIFTUNG**



Elterninitiative  
ME/CFS-krankte Kinder &  
Jugendliche München e.V.

**ME/CFS**  
DEUTSCHE GESELLSCHAFT  
FÜR ME/CFS E.V.



Post-COVID **kids** Bavaria



Menschen für Kinder e.V.  
Jeder kann helfen



Lost Voices Stiftung



Zentrum für Schmerztherapie junger Menschen

**BAYNET FOR MECFS**  
Bayerisches Netzwerk zur Erforschung von ME/CFS



Staatliche Schule  
für Kranke München



**MAX PLANCK INSTITUTE**  
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DEUTSCHE GESELLSCHAFT  
FÜR KINDER- UND JUGENDMEDIZIN e.V.



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