TOPx HHS Tech Sprint · Invisible Illness track · Phase 2 submission

Help For Long COVID

The review site for neglected chronic illness:
Clinicians and treatments, reviewed by people who have been there

Who will believe me, and what has helped people like me?

18,700	1,100	1,500	Free
provider pages	treatment and test pages	pharmacies	live now

helpforlongcovid.com · Co-founded by Stephanie Mattera and Salvatore Mattera (who lived with Long COVID for years)

People with Long COVID ask two questions:

Finding a clinician

Who will believe me?

Finding what helps

What helps?

The gap

Women are disproportionately affected.

Federal data counts Long COVID diagnoses, but no federal registry says which clinicians treat it.

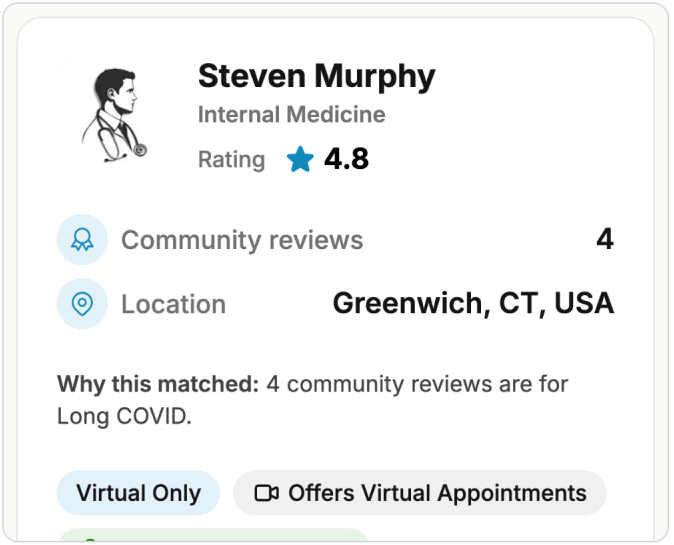
There is no NUCC taxonomy code for Long COVID or ME/CFS care.

Source: NUCC Health Care Provider Taxonomy code set; TOPx Invisible Illness challenge statement

Find clinicians people with your illness have already seen, across 18,700 providers

1. Visitors choose an illness, such as Long COVID, and filter by location, specialty, treatment, and reviews.
2. Every card says why it matched.
3. Read reviews, save interesting doctors to your profile, then contact the practice to schedule an appointment.
4. Star ratings come from community reviews, not from us.

On the live site

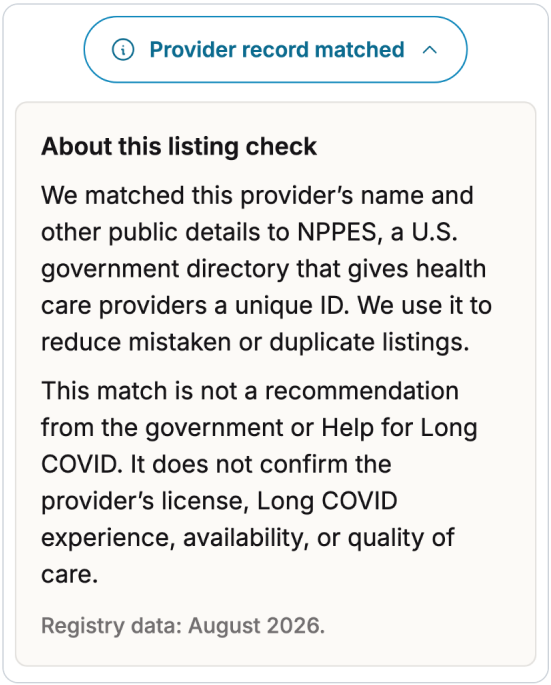


Live site · helpforlongcovid.com/care-providers

Listings are checked against NPPES, the federal provider registry

1. Listings are matched to the CMS NPPES public file. The "Provider record matched" badge names the registry and the file month (August 2026).
2. The badge says plainly what a match covers and what it does not.
3. Every illness label says where it came from, such as community reviews, the provider's own website or an illness organization's directory.

On the live site: Jordan Vaughn's listing



Live site · helpforlongcovid.com/care-providers/jordan-vaughn · Source: CMS NPPES public file, August 2026

Treatment pages show what helped and what didn't, from people who tried it

1. Covers prescription and over-the-counter medications, supplements, procedures, lifestyle changes and routines (including off-label uses such as low dose naltrexone).
2. What helped and what did not, each with a link to its source.
3. "Community experience" counts appear once five or more people have reported, so no single voice speaks for everyone.
4. Every review records the reviewer's illness, symptoms treated, change per symptom, side effects, dose, cost per month and insurance coverage.

On the live site: low dose naltrexone

Listing summary

Positives

- Several people reported that even small nightly doses (0.25–2.5 mg) “helped my fatigue” within weeks as they slowly titrated upward Mayo Clinic Connect.

Negatives

- Multiple posters noted zero benefit for POTS-type light-headedness even at 4.5 mg or higher, despite fatigue improvements Reddit.

Live site · helpforlongcovid.com/treatments/ldn-low-dose-naltrexone

Built with patients: 27 advisor check-ins, 21 changes shipped

27

advisor check-ins since August

21

changes now live on the site

Brain Fog Mode

Darker, dimmer and motion-free, one switch at the top of every page.

Easier search

Search got the most fixes of any part of the site.

Source: advisors' check-in forms, August to October 2026

IN Federal data
OUT A standards-based provider list

IN · Coming in

CMS NPPES
Live · August 2026 file · badge on matched listings

VA Long COVID counts
Live · 11,117 U09.9 entries, fiscal 2025; the CDC series stopped in 2024

PubMed Central
Live · cited by fifteen test guides

ClinicalTrials.gov
In identity review · coming to listings next

Help For Long COVID

Federal data can't show who treats Long COVID: NPPES has no code for it.

Patients can. We join their reviews to the federal record.

AI reads provider websites to check locations; real people confirm.

OUT · Going out

The website
Live · free for everyone

FHIR R4 Plan-Net provider list
Passes HL7 validation · working towards an open release, not published yet

CURE ID handoff
Live · prepared summaries today; data exchange once FDA and NCATS terms are agreed

Status as of October 2026 · Every source explained at helpforlongcovid.com/resources/where-our-data-comes-from

Faster decisions about who to see and what to try

Better decisions

Reviews record cost per month, insurance coverage, dose and side effects, so people can weigh a treatment before raising it with their doctor.

Less wasted effort

A short list of clinicians that people with the same illness have actually seen, instead of cold-calling practice after practice.

Fewer barriers

Free, no login needed to browse, and Brain Fog Mode for the hardest days.

Insight for research

A prepared summary lets people share what they tried with CURE ID, the FDA and NIH treatment registry.

Live and improving: nine production releases since the October 1 Beta demo

Our goals from Phase 1 of this sprint: two live, two in progress

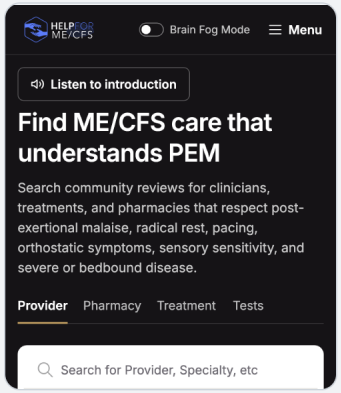
Phase 1 goal	Status	Where it stands
NPPES-corroborated profiles	**Live**	Badge on matched listings, saying what the match covers
Treatment experience summaries	**Live**	Counts of what people reported, per treatment
Open provider dataset	**In progress**	Exported and validated as FHIR R4 Plan-Net
Clinicians from ClinicalTrials.gov	**In progress**	Scanned; identity review under way
Time to a believing clinician	**Next**	Starts with an HHS methods expert, our ask in this submission

Ready to scale: our platform already serves 24 related illnesses

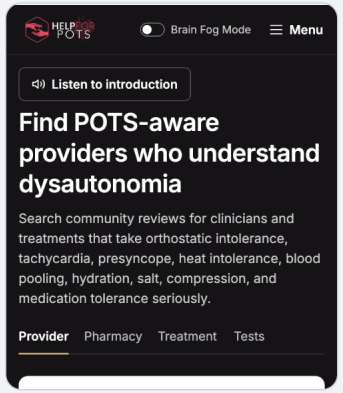
Every illness gets its own front door

The same directory, reviews and label sources serve Long COVID and 24 other illnesses, each at its own address.

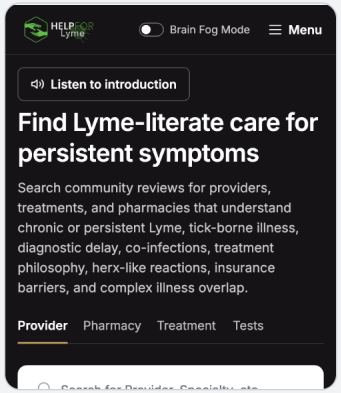
Also live (sample): **helpforeds.com**, **helpforfibro.com**, **helpfordysautonomia.com**



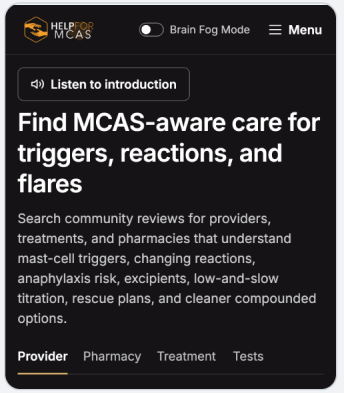
helpformecfs.com



helpforpots.com



helpforlyme.com



helpformcas.com

Standard format

The provider list exports as FHIR R4 Plan-Net, the format payers use for directory APIs. A clean-room test loaded it using only our export instructions.

Policy endgame

No NUCC taxonomy code exists for this care. An open, corroborated list of who provides it could become the evidence base NUCC and CMS need to create one.

Key assumptions

Listings stay accurate through provider and reader corrections, people keep sharing experiences, and human review keeps pace.

Each address opens its illness page on helpforlongcovid.com

Being believed starts with finding the right clinician.

The CDC's Household Pulse series stopped in 2024, VA records counted 11,117 Long COVID (U09.9) entries in fiscal 2025, yet no federal directory shows who treats these illnesses.

A free site where people discover clinicians others recommend, what treatments people try, and what the federal record says is built to shorten the path to diagnosis.

Sources: CDC Household Pulse Survey; VA data via helpforlongcovid.com/resources/federal-long-covid-data

Demo path Public pages, no login needed

Everything shown in this deck is live: check it in five minutes

1. Switch on Brain Fog Mode in the header
   helpforlongcovid.com
2. Choose Long COVID with "Providers with Reviews Only" switched on
   helpforlongcovid.com/care-providers?has_reviews=1
3. Open the "Provider record matched" badge
   helpforlongcovid.com/care-providers/jordan-vaughn
4. See what helped and what did not
   helpforlongcovid.com/treatments/ldn-low-dose-naltrexone
5. Read federal Long COVID data in plain language
   helpforlongcovid.com/resources/federal-long-covid-data

Every page in this path is public and free

Prize funds would allow us to reach more people with better information



1 **Reach people searching for care → more visitors**

A targeted search and social campaign aimed at the questions people already ask. We measure what works and grow it.

2 **Partner with clinics and pharmacies → better information**

Publish what people struggle to find today, such as prices and which insurance they accept.

3 **Keep human review at pace → listings people trust**

Human review of provider locations, illness labels and new submissions as reviews grow.

What's next

We'll build

A clinical trials directory, built from ClinicalTrials.gov

Data exchange with CURE ID, the FDA and NIH treatment registry, once terms are agreed

HHS can help with

A research methods expert, to measure how long it takes to find a clinician who believes you

Introductions to medical societies

Thank you

helpforlongcovid.com · free to use, no login needed