



4 decades of prescribing. Delayed harm. Many diagnoses, rarely linked to FQs.

Missed. Untracked. Uncounted.

Fluoroquinolone-associated disability (FQAD)

Johanna Ihli, BSN

Independent Researcher, Kinder, Louisiana, USA | druginducedmito.org/fqad

>1 billion

fluoroquinolone courses, US and EU/EEA community care since 1987*

0

registries for patients with FQAD

0

long-term studies following patients with FQAD

Millions?

people affected. No one has counted.

A decade after FDA recognised fluoroquinolone-associated disability (FQAD), no health system systematically identifies, registers or longitudinally follows these patients.

1 THE PROBLEM

PATIENTS ARE NOT FULLY INFORMED

Informed consent has not kept pace with the seriousness of the warnings.
FDA Citizen Petition FDA-2026-P-5116 asks for change.

UNNECESSARY EXPOSURE CONTINUES

Prescribing outside recommended uses continues (EMA, 2023), including military prophylaxis with no long-term follow-up.

DIAGNOSED IN PIECES

Patients report labels such as fibromyalgia, ME/CFS, dystonia, MCAS, MS and lupus. The fluoroquinolone link is rarely made.

THE RESULT

Without a count, the injury stays “rare.”
**It's not rare.
It's rarely counted.**

The barrier is not a lack of knowledge or data systems. It is the failure to connect and consistently use what already exists.

2 THE IMPACT

Not abstract safety signals. Severely injured PATIENTS.

Talia Smith linktr.ee/finding.vulneraries



Talia: FQAD after 3 Cipro pills

Bobby Caldwell, singer/songwriter bobbycaldwell.com



(1951–2023) Devastating decline after Levaquin for “sniffles”

3 WHAT IS NEEDED NOW?

You can't treat what you don't count.

IDENTIFY & COUNT

Adopt a standard case definition, then use existing data networks and a registry to measure incidence and prevalence.

RESEARCH & TREATMENT

Study mechanisms and test treatments, so care is based on evidence, not guesswork.

FOLLOW

Track treatments tried, recovery, disability and long-term outcomes at fixed intervals.

After four decades, these patients deserve more than recognition. They deserve answers and treatment.

4 CALL TO ACTION

Researchers. Doctors. Nurses. We need you.

We invite collaboration from clinicians, epidemiologists, pharmacovigilance experts, regulators and registry partners to help build the infrastructure needed to identify, count and longitudinally follow patients with FQAD.

Clinicians: ask about fluoroquinolone exposure, document reactions to prevent re-exposure, and report suspected cases. Support the US regulatory petition on informed consent: **FDA-2026-P-5116** ([regulations.gov](https://www.fda.gov/regulatory-information/search/fda-search), open until November)

druginducedmito.org/fqad **FQ100.org**

Virtual Problem Clinic

November 2026 · hosted by BMJ Future Health

References: 1. FDA Advisory Committee briefing, 5 Nov 2015. 2. FDA Drug Safety Communications, May and Jul 2016. 3. EMA Article 31 referral, 2018–19; reminder, May 2023. 4. Kabbani S, et al. Clin Infect Dis 2018;67:134–6. 5. Adriaenssens N, et al. J Antimicrob Chemother 2021.

*Conservative lower bound from published US prescribing and ECDC consumption data, 1987–2025. Counts courses, not people. Excludes hospital and military use. Photos shared with permission of Talia Smith and Mary Beth Caldwell; captions are patient and family testimony.