Working together to improve FND support

FND Connect brings together lived experience, accessible education, practical support and digital tools. We want to work with healthcare professionals and organisations to make better support available to people affected by FND.

FND Connect is an independent Community Interest Company. It is not part of the NHS and a conversation, enquiry or directory listing does not mean NHS endorsement.

1. Who we are

FND CONNECT CIC is a UK Community Interest Company, company number 17313147. We exist to close gaps in understanding, information and practical support for people living with Functional Neurological Disorder.

2. The problem we address

People with FND often leave a diagnosis without clear next steps, usable information, or a way to organise symptoms between appointments. Services are stretched. Independent, accurate, non-clinical support can sit alongside clinical care without replacing it.

3. Existing services

- SeizeControl — Free seizure and symptom recording. Appointment-ready summaries from the person's own records. Not a diagnostic system or emergency monitor. (https://fndconnect.org.uk/seizecontrol/)
- FND Passport — A patient-controlled profile for communicating needs and important information. The person decides what to share. (https://fndconnect.org.uk/passport)
- FND-aware clinician directory — A searchable register of reviewed clinician and service listings. Separate from organisational partnerships. (https://fndconnect.org.uk/clinicians/directory)
- Research portal — Aggregated, anonymised SeizeControl insights. Verified clinicians see additional aggregate views. That is not project-specific research access. (https://fndconnect.org.uk/research/)
- Professional FND training — Seven existing courses covering adult and paediatric healthcare, schools, colleges, workplace, social care and family carers. Certificates of Completion are CPD-accredited by FND Connect under the CPD Charter. They are not externally accredited and they are not regulated clinical qualifications. (https://fndconnect.org.uk/training/)
- Start here — A calm first path after diagnosis, suitable to share without overwhelming someone. (https://fndconnect.org.uk/start/)
- Appointment preparation — Structured questions and information to take to clinic. (https://fndconnect.org.uk/appointment-pack/)
- GP leaflets — Free printable patient information leaflets for general practice and clinics. (https://fndconnect.org.uk/for-gps/)
- Community and virtual groups — Local and virtual peer support. Peer support does not replace clinical care. (https://fndconnect.org.uk/support-groups/)
- Practical support — Advocacy, disability-related guidance and routes to grants where available. (https://fndconnect.org.uk/support/)

Partnership opportunities

4. How organisations can work with us

- Patient information and signposting: Add FND Connect resources to existing patient information and discharge processes, without transferring identifiable patient data.
- Digital tool collaboration: Explore how existing tools might support communication, symptom recording and appointment preparation — with clear clinical-safety boundaries.
- Clinical and professional education: Use the existing seven-course catalogue, book for a team, or discuss a separate educational arrangement.
- Research and academic collaboration: Propose a project involving lived-experience participation, existing services or eligible aggregated data. Every proposal is reviewed before FND Connect commits.
- Patient and public involvement: Facilitate meaningful lived-experience perspectives. People with FND should help shape relevant work, not only supply data.
- Institutional and strategic partnerships: Regional pathways, awareness, education campaigns and sustainable community support — documented in writing.

5. Governance and safeguarding

Partnerships are permission-based. Resource sharing is operational. Formal institutional relationships, paid work, clinical pilots and research each need the matching approvals. Research data is not a general-access resource. Safeguarding and privacy policies are published at https://fndconnect.org.uk/governance/

6. Impact evidence

Live organisational figures are published at https://fndconnect.org.uk/impact/. Professional partnership counts (enquiries, active collaborations, resource downloads) are reported separately and are not mixed into a single headline with website visits or social reach.

7. Proposed next steps

- Download the Professional Resource Pack and share public information where it helps.
- Use the enquiry form at https://fndconnect.org.uk/professionals/partnerships/enquire/
- For research, submit a structured proposal. An enquiry does not grant data access.

8. Contact

FND CONNECT CIC
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https://fndconnect.org.uk/professionals/partnerships/