



FND North
Morecambe
Lancashire

04/10/2024

Dear Sir/Madam,

We write in support of Professor Terry's application for an EPSRC award.

FND North is an emerging non-profit organization dedicated to providing comprehensive support for individuals suffering from Functional Neurological Disorder (FND) in the North of England. Our mission encompasses the entire spectrum of patient care, from diagnosis through to treatment and ongoing support.

Currently, we have approximately 50 to 60 individuals who have expressed interest in collaborating with the charity. FND North is committed to guiding patients in their quest for appropriate treatment options within the region, offering resources and referrals to relevant care facilities. Additionally, we plan to establish monthly drop-in centres across England, creating opportunities for individuals to connect and share experiences.

The breadth and depth of support provided by FND North will be extensive. By actively involving patients with lived experiences, we aim to gain valuable insights into the specific needs and desires of the community. This data will facilitate targeted research initiatives, including surveys and follow-up questionnaires, enabling us to assess the needs of a representative sample of individuals with FND.

The founder of FND North, Matthew, brings five years of personal experience with Functional Neurological Disorder. Diagnosed in 2019 at Lancaster Royal Infirmary, Matthew has since pursued treatment at renowned institutions such as King's College London and St George's Hospital London. During his time there, he participated in a randomized controlled trial of Specialist Physiotherapy for Functional Motor Disorder under the guidance of Dr. Jan Coberg. Matthew is currently receiving ongoing treatment from Dr. Abhijit Das at Preston Royal Hospital.

With FND North, we aspire to create a supportive network that empowers patients, fosters community engagement, and enhances the overall quality of care for those affected by Functional Neurological Disorder.

Katerina is a patient advocate that will also partner on the project. She has a BA (Hons) in Sociology and Applied Social Studies. This provides her with a foundational understanding of research methodology. As for FND expertise, she has 15 years lived experience with FND post viral infection. She experiences severe and debilitating neurological and cognitive symptoms, including a Functional Movement Disorder (FMD) - Paroxysmal Dystonia. She has first hand experience of the lack of awareness and treatment for FND in the NHS; having taken nine years to receive an accurate diagnosis and no FND targeted treatment for her movement disorder. She is passionate about contributing her experience towards improving much needed rehabilitation treatment for FND. She has participated in numerous research studies with the University of Manchester and King's College London, provided feedback on a postgraduate research proposal, contributed to PPI discussions at a N-Code co-creation workshop, and now collaborates as a patient advisor on various FND research projects with the same team; providing valuable insights as a woman living with FND, of which 75% are disproportionately affected, to guide appropriate targeted rehabilitative novel technologies and therapeutic modalities.



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We add the benefit of experience working together with both Dr. Abhijit Das and Dr. Anirban Dutta on existing FND novel technology development research projects. Therefore, we know what to expect in terms of contribution and have become accustomed to providing feedback and critical opinion on development of technologies for use with FND. We feel this provides us with valuable insights that would benefit the project.


We are particularly excited by the prospect of a Knowledge Accelerator and can envisage our engagement and participation with this accelerator in several ways. We anticipate that our involvement with the project will result in an in-kind contribution of £20,000 over a period of three years.

- Sharing of opportunities to participate within our network
- Attendance and contribution in both online and in-person meetings/workshops and other engagement activities.


Yours Sincerely,

Matthew Newsham
Founder of FND North and FND Patient Advocate.

Miss Katerina Hatjipanagioti
FND Patient Advocate

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