



Dear Sir/ Madam,

FND Hope is a patient advocacy group providing support for patients diagnosed with Functional Neurological Disorder (FND). We work closely with international experts in the field, including Dr. Mark Edwards and Dr. Jon Stone. We, as a patient group, feel that a physiotherapy approach would be invaluable for our members.

Most of our members prefer physiotherapy to psychological approaches because many find it is more relevant. Physiotherapy offers an opportunity for patients to become physically mobile and self-reliant again. As patients regain motor control they also reclaim their independence, which also has a positive impact on their mental health. Properly administered physiotherapy improves the overall quality of life for patients with functional motor symptoms. This improvement to over-all quality of life can aide in keeping patients' healthcare cost to a minimum.

Physiotherapy is the most beneficial resource available for those with functional motor impairments, but there is limited availability. We would strongly support the addition of one (or more) specialist physiotherapists to the fledgling service for patients with FND in your area, and hope more physiotherapists will become available to cover a wider catchment area in the future.

Yours Sincerely,

Bridget

Bridget Mildon  
President/Executive Director, FND Hope, Inc.



## FND Hope's Call for Physio/Physical Therapy

We believe patients have a tremendous amount to gain from properly administered physiotherapy, and it is imperative that FND patients receive physiotherapy tailored to them. Our information is based off extensive studying of research articles and from interacting with over 1,000 patients diagnosed with Functional Neurological Disorder.

Many patients cannot contribute their onset of symptoms to current or past emotionally traumatic events. Because many patients become symptomatic after accidents, surgical procedures and as a result of underlying medical conditions, they often have a difficult time trusting the FND diagnosis.

It is a difficult concept for anyone to grasp why such a strong emphasis in psychology treatments exists when mental health symptoms do not typically manifest, and loss of neurological function does.

FND patients in general find they benefit the most from physiotherapy, and they are eager and willing to participate. Once many patients begin to re-learn natural movements many find their brains innately repair rather quickly.

Physiotherapy is the most beneficial resource available for those with a Functional Neurological Disorder diagnosis. Becoming ambulant again and learning techniques to remain mobile is not only advantageous for patients, but in the long run, it is the most cost efficient use of resources and most likely to keep patients' healthcare cost to a minimum.

While some FND patients do not have psychological trauma before their FND diagnosis, many develop significant distress as a result. Most patients feel stigmatized by healthcare professionals because of their FND diagnosis, and they find this often becomes a roadblock in their care. This experience then becomes its own form of medical trauma and takes on a life of its own. This of course begins to feed the never-ending cycle of symptoms and stress. The loss of motor control in and of itself has a significant impact on a patient's mental health and taking on the prejudices of our society compounds the symptoms.

We feel it is imperative for patients to receive properly administered physiotherapy tailored to their specific needs as soon as possible. Hesitations to provide physio services, long wait times and untrained physiotherapist will all have a negative impact on patients' healthcare in general and increase costs accrued to treat FND patients.

We hope by working together, we can empower patients to better health.



### Why do patients need physiotherapy?

- a. There is growing evidence that physiotherapy can be very effective (Gelauff et al., 2014b) (Nielsen et al., 2013)
- b. Short-term and long-term successful outcomes were documented in the treatment of patients with functional movement disorders by a rehabilitative, goal-oriented program with intense physical and occupational therapy. The rapid benefit, which was sustained in most patients, suggests substantial efficacy that should be further assessed in a prospective, controlled, clinical trial. (Czarnecki. . .2011)
- c. Physiotherapists in general are interested in treating such patients and feel physiotherapy to be an appropriate treatment. However, inadequate service structures, knowledge and support from non-physiotherapy colleagues are judged to be barriers to provision of care. (Edwards., 2012)
- d. There are specific interventions and approaches that seem to work, and are amenable to study e.g. unlearning maladaptive motor programs, ignoring negative movements, focusing on complex motor programs as a whole (i.e. not focusing on a paralysed leg, for example, that might be the case for a non-specialised physiotherapist) (Nielsen et al., 2013)
- e. The most successful programs appear to do this by conceptualizing the FMD as a problem with abnormally learned “motor programs” in the brain that have to be “unlearned” (Nielsen et al., 2013)
- f. Most physiotherapists questioned in a study felt that they could do more to help FND patients, but felt poorly supported by neurologists and existing service structure (Edwards et al., 2012b)

1. Gelauff JM, Dreissen YE, Tijssen MA, Stone J. Treatment of Functional Motor Disorders. Current treatment options in neurology 2014b; 16: 1-15.

2. Nielsen G, Stone J, Edwards MJ. Physiotherapy for functional (psychogenic) motor symptoms: A systematic review. Journal of psychosomatic research 2013; 75: 93-102.

3. Czarnecki K, et al., Functional movement disorders: Successful treatment with a physical therapy rehabilitation protocol, Parkinsonism and Related Disorders (2011), doi:10.1016/j.parkreldis.2011.10.011

4. Edwards MJ, Stone J, Nielsen G. J Neurol Neurosurg Psychiatry (2012). doi:10.1136/jnnp-2011-302147