



FND – Past Present and Future

Prof Jon Stone

Cons Neurologist (NHS Lothian)

Professor of Neurology (University of Edinburgh)

Twitter: @jonstoneneuro

www.neurosymptoms.org

What is a functional disorder?

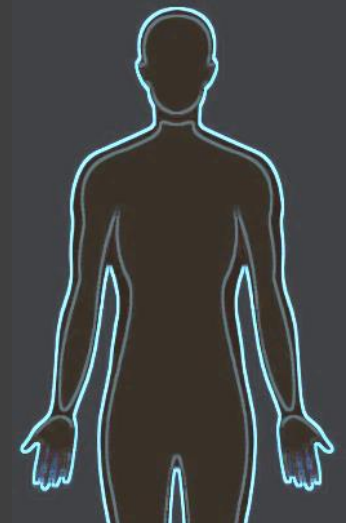
Structural

Brain tumour, MS



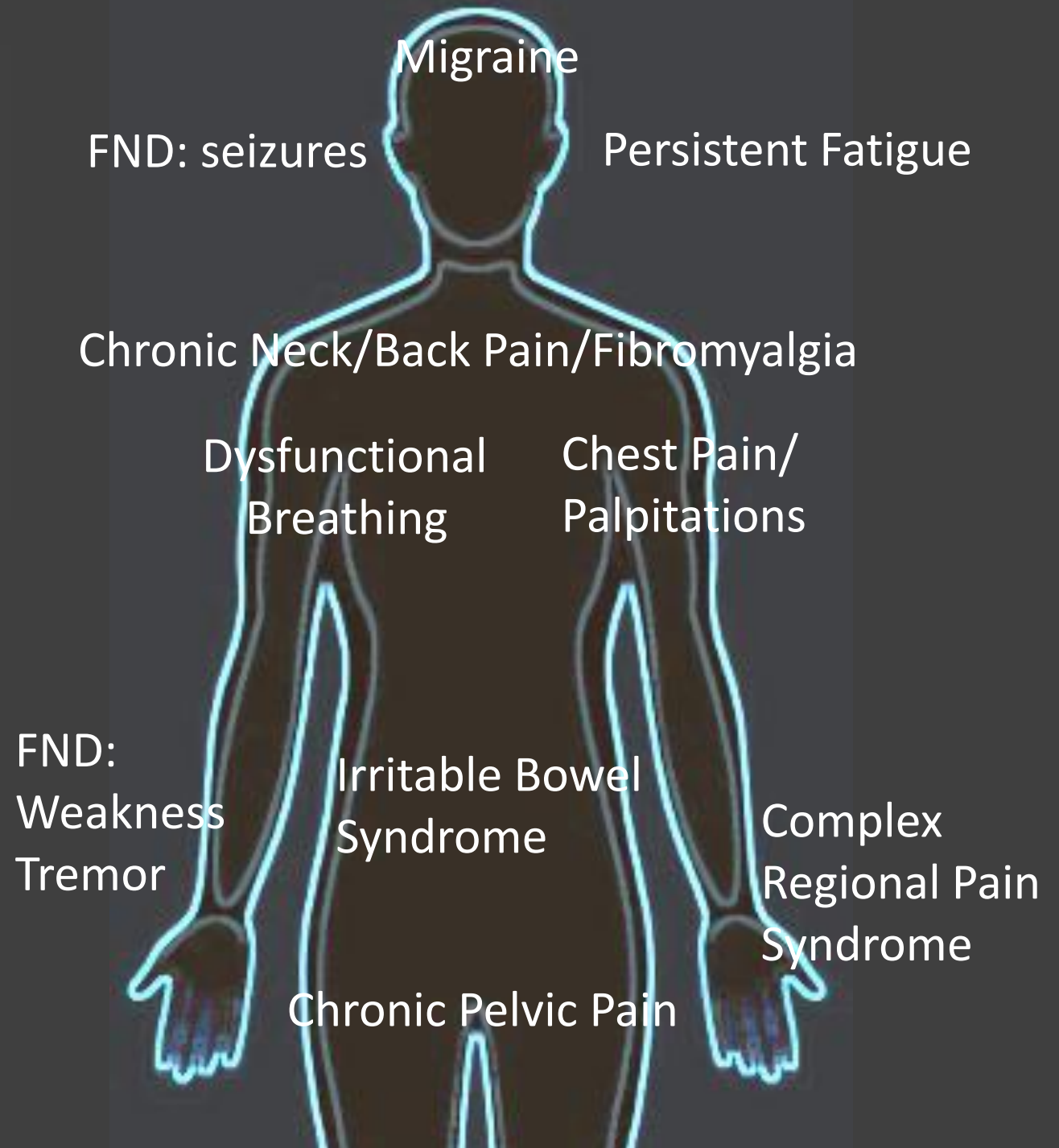
Function

FND, Migraine



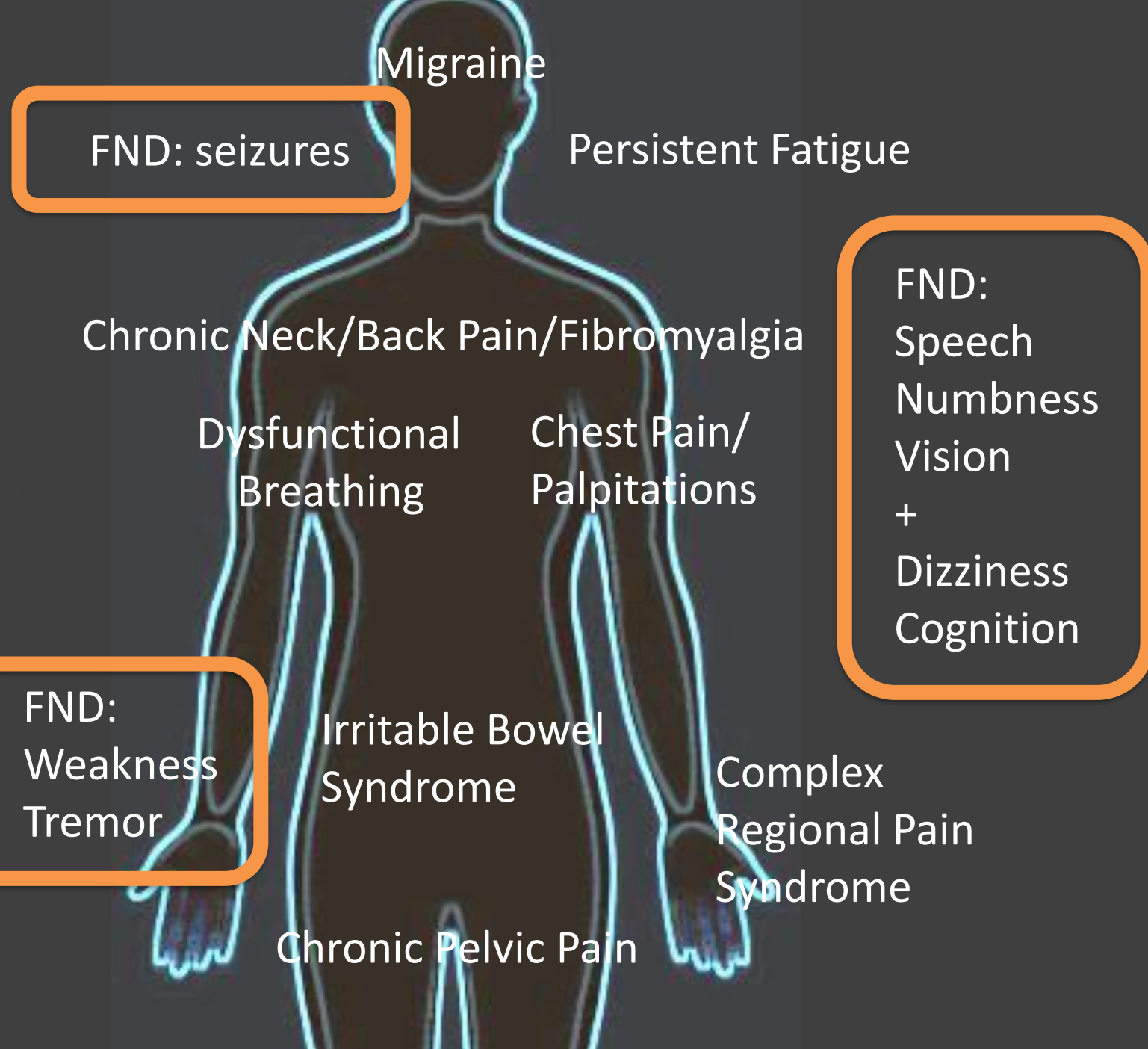
Functional Disorders: everyone's problem

Up to a 1/3 of patient
visits



Functional Neurological Disorder

2nd commonest reason to
see a neurologist

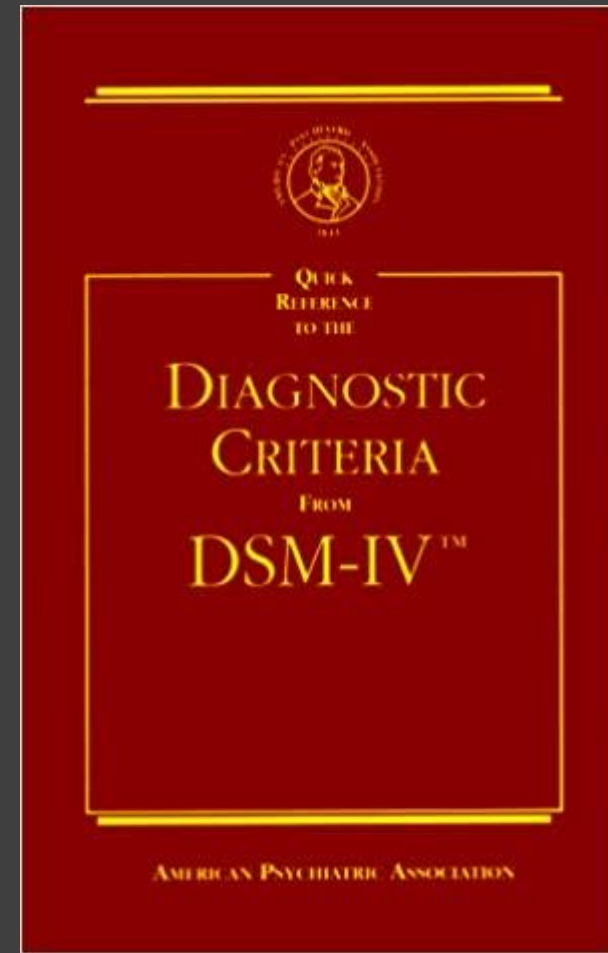
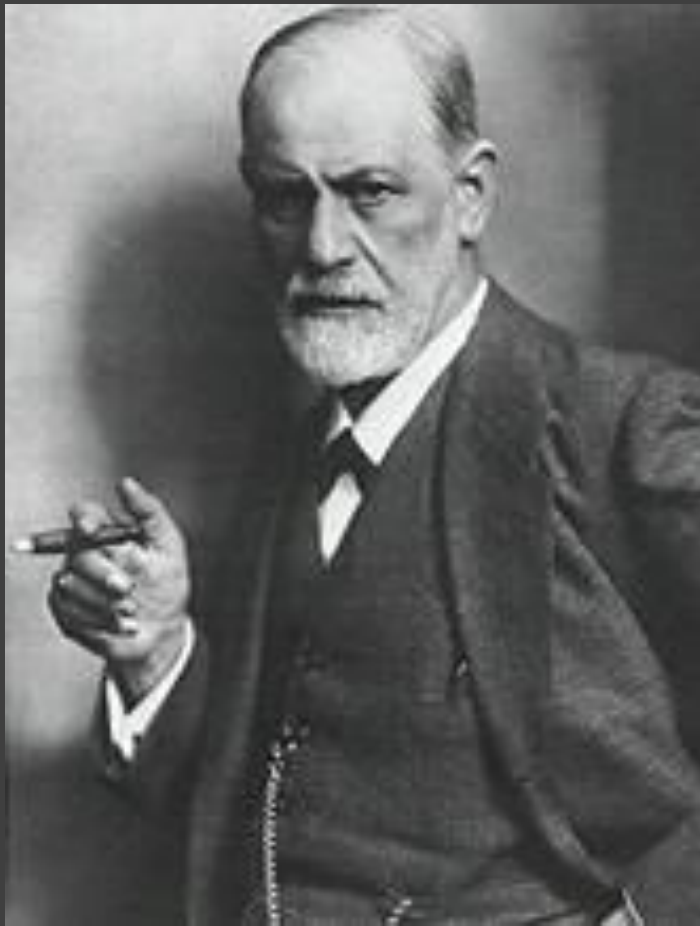




FND in the 19th century



Shell shock – FND in World War One



Conversion Disorder – 20th Century Sigmund Freud



As a junior doctor
in 2004 with my
wife Pam and two
children

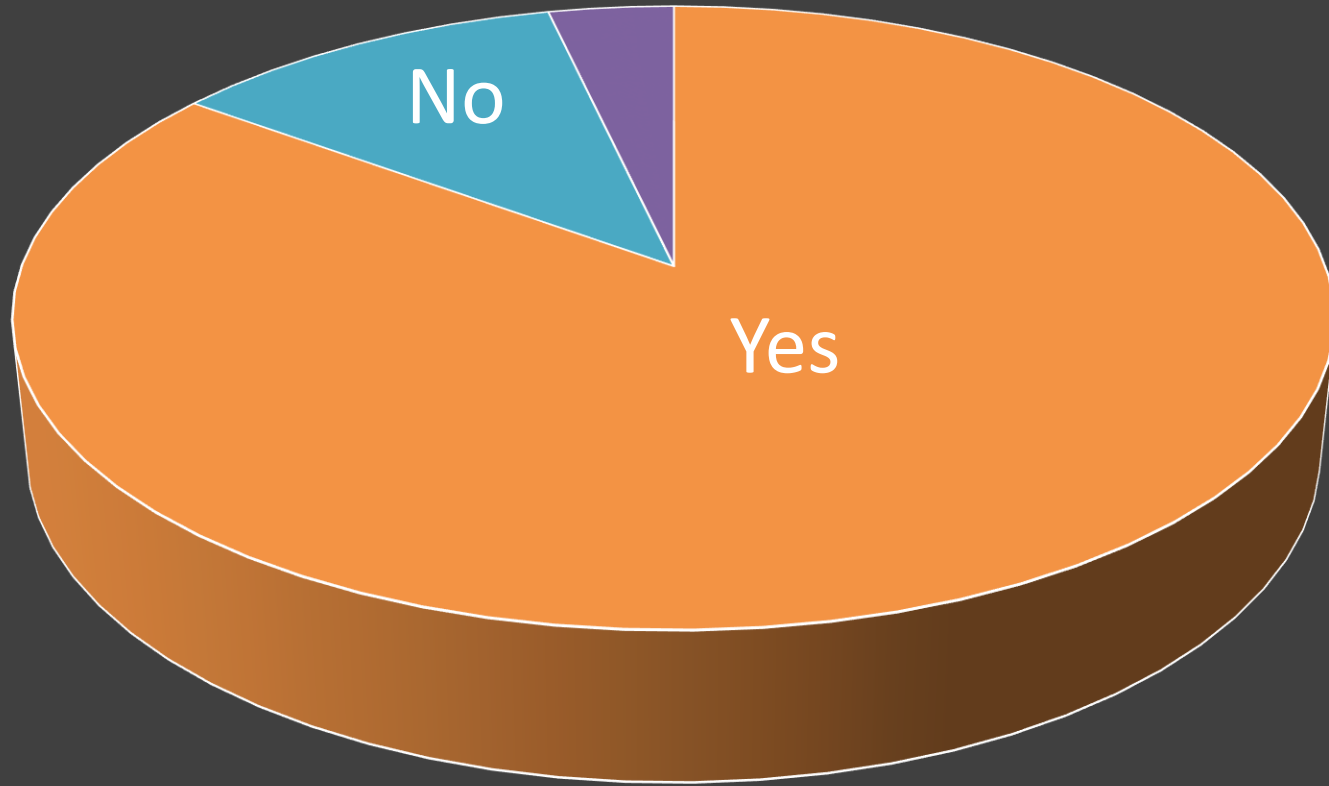


“Theres nothing wrong....”

“It’s a psychological problem...”

“Your tests are normal...goodbye”

‘Have you ever felt dismissed or disrespected when visiting a medical professional?’



508 people with FND



FND research in the 2020s

Its common
and disabling

FND diagnosis
reliable as
others

Diagnosis of
Inclusion

Neurological
AND
Psychological

Not
malingering

Treatment
needed and
can help

FND is disabling, and real



Its common and disabling

- 1997-1999 Alan Carson

MD looking at epidemiology of 'symptoms unexplained by disease' in neurology clinic



Disability, distress and unemployment in neurology outpatients with symptoms 'unexplained by organic disease'

A Carson,¹ J Stone,¹ C Hibberd,¹ G Murray,² R Duncan,³ R Coleman,⁴ C Warlow,¹ R Roberts,⁵ A Pelosi,⁶ J Cavanagh,⁷ K Matthews,⁵ R Goldbeck,⁴ C Hansen,¹ M Sharpe¹



Alan Carson
Neuropsychiatry



Michael Sharpe
Liaison
Psychiatry



Charles Warlow
Neurology

Frequency of Functional Disorders in Neurology

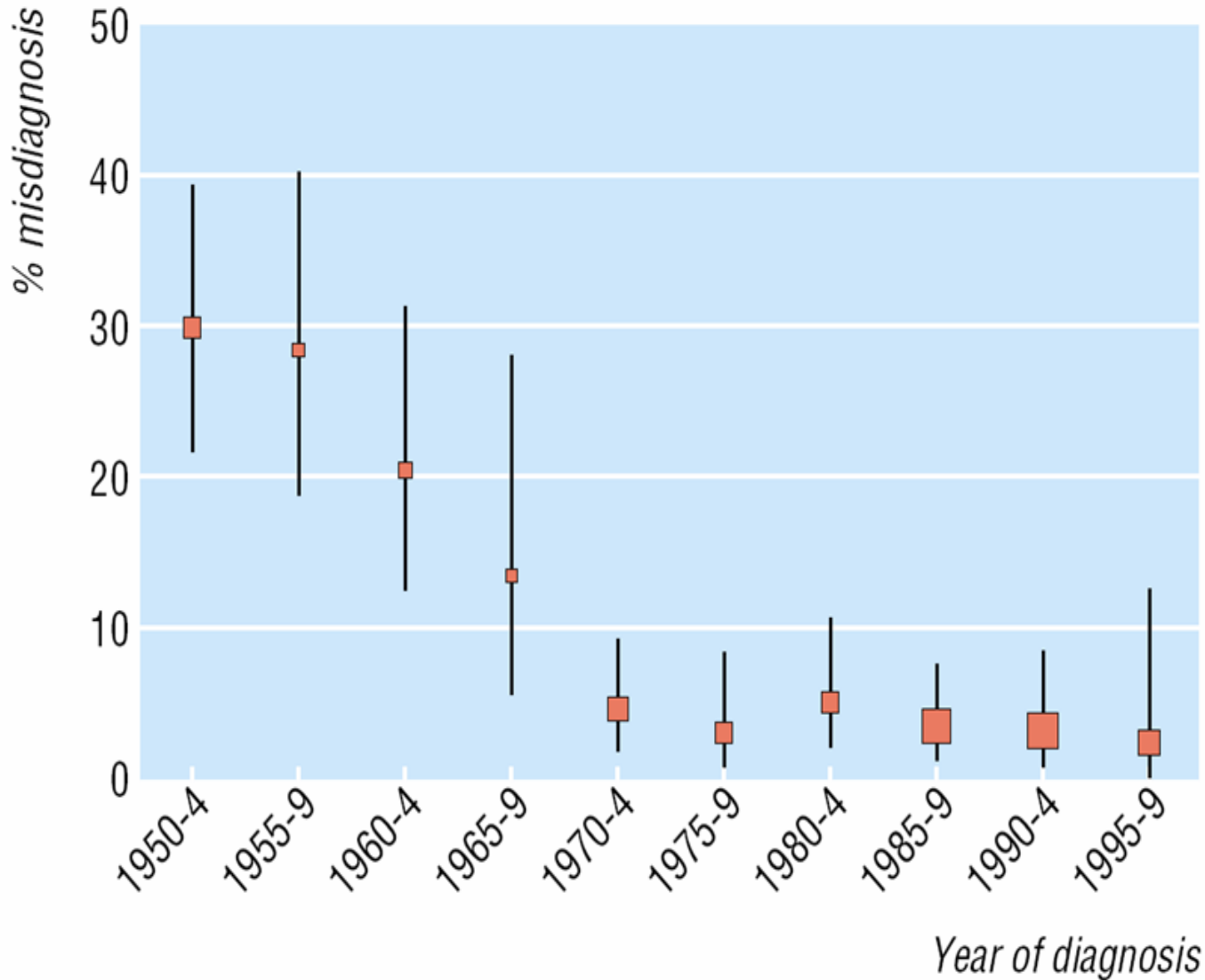
3781 New Neurology Outpatients across Scotland.

Headache	19%
Functional Disorders (Seizures (n=85), Weakness (n=56), Sensory (n=71))	16% - 6%
Epilepsy	14%
Peripheral Neuropathy	11%
Multiple Sclerosis	7%
Movement Disorder	6%
Spinal Disorder	6%
Syncope	4%
Stroke	3%



FND Diagnosis as
reliable as others

Misdiagnosis of FND



Stone et al. *BMJ* Oct 2005. 27 studies; 1466 patients followed for median of 5 years

doi:10.1093/brain/awp220

Brain 2009; 132; 2878-2888 | 2878

BRAIN
A JOURNAL OF NEUROLOGY

Symptoms 'unexplained by organic disease' in 1144 new neurology out-patients: how often does the diagnosis change at follow-up?

Jon Stone,^{1,*} A. Carson,^{1,*} R. Duncan,² R. Coleman,³ R. Roberts,⁴ C. Warlow,¹ C. Hibberd,¹ G. Murray,⁵ R. Cull,¹ A. Pelosi,⁶ J. Cavanagh,⁷ K. Matthews,⁴ R. Goldbeck,³ R. Smyth,¹ J. Walker,¹ A. D. MacMahon⁸ and M. Sharpe¹

4 misdiagnoses out of 1144 patients over 18 months

doi:10.1093/brain/awz138

BRAIN 2019; 0; 1-12 | 1

BRAIN
A JOURNAL OF NEUROLOGY

The prognosis of functional limb weakness: a 14-year case-control study

Jeannette M. Gelauff,^{1,2} Alan Carson,¹ Lea Ludwig,¹ Marina A. J. Tijssen² and Jon Stone¹

1 misdiagnosis out of 107 patients over 14 years

Diagnosis of Inclusion

FND should be diagnosed using positive signs



Functional Neurological Disorder (FND)
- an introduction

Jon Stone · 4.3K views

An introductory film about the diagnosis and treatment of FND
completed in December 2018 by the Dutch film company ITZIT

8:12

ns.org

Functional Dystonia



'When you look at the foot, you can see that it is bent, obviously?' 'Yes'.

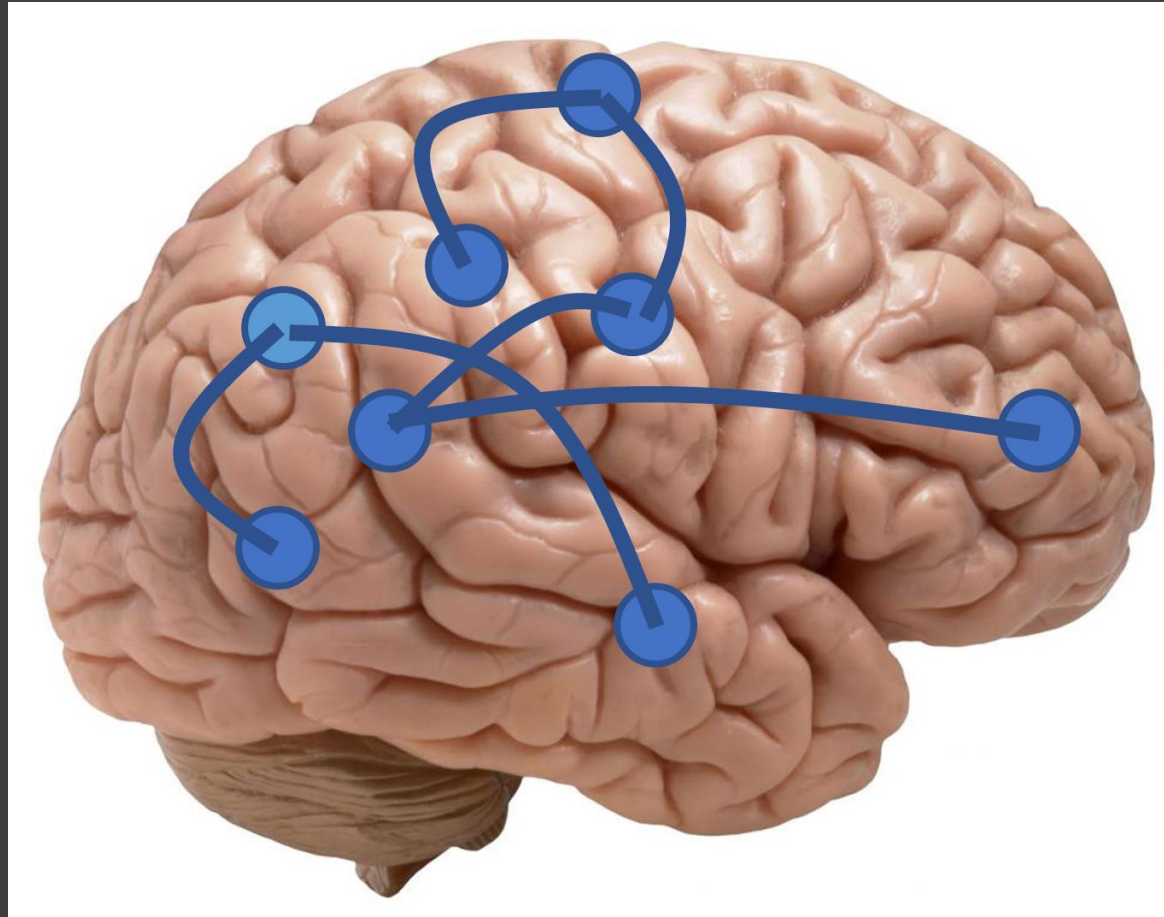
Neurological and Psychological

'Organic' and 'non-organic': a tale of two turnips

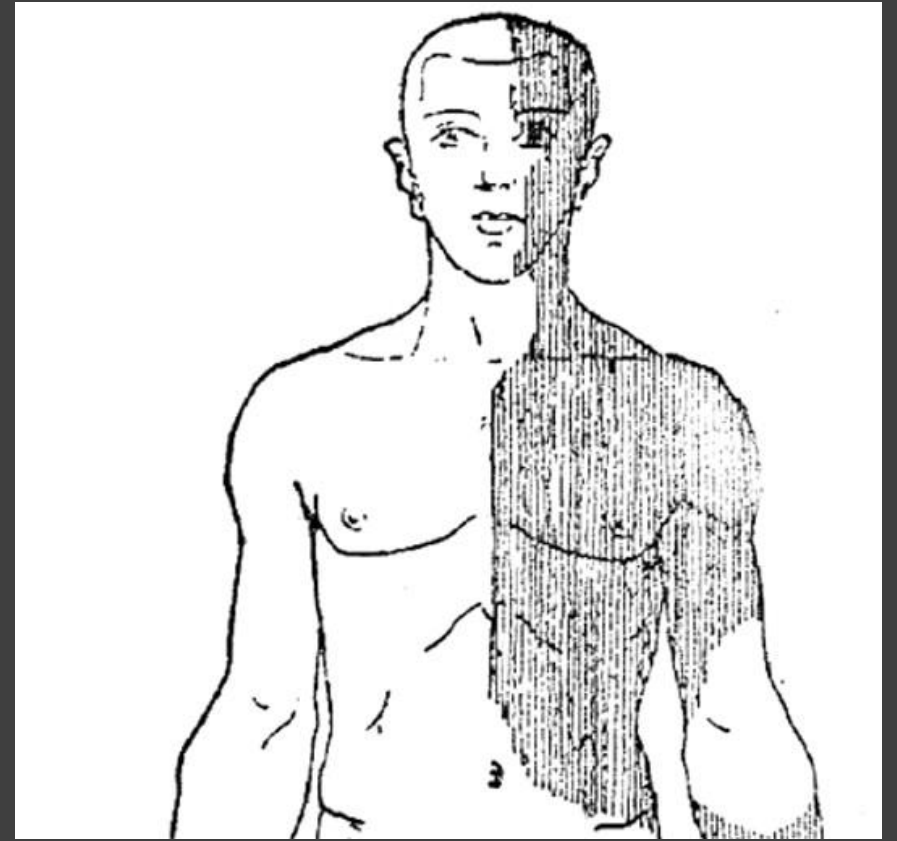
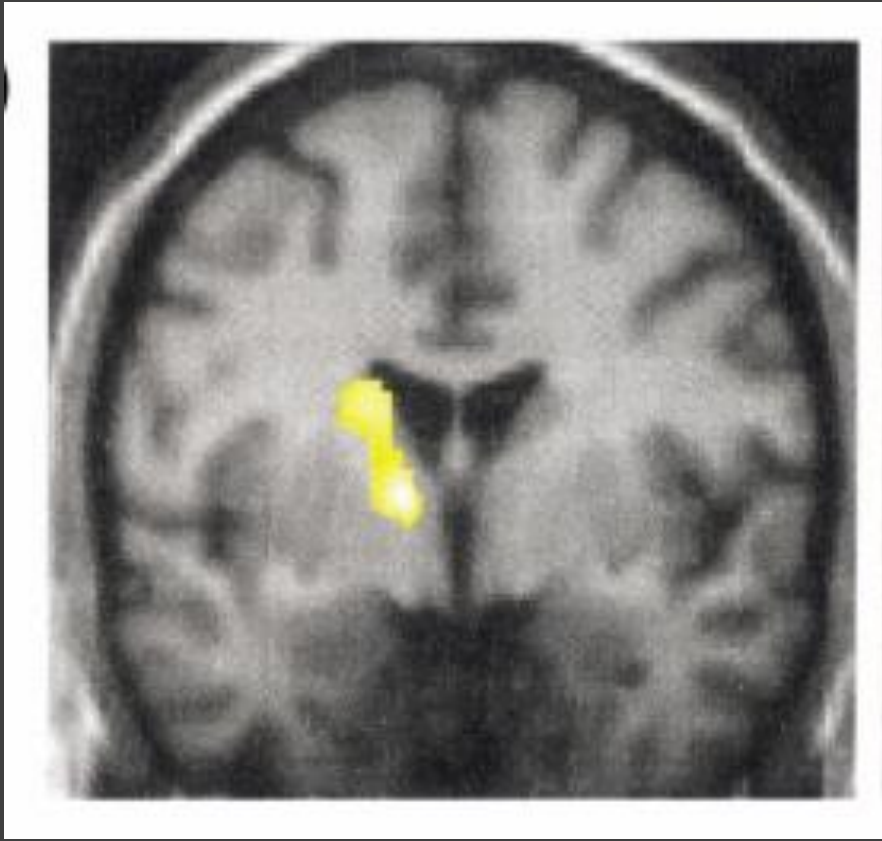
Jon Stone, Alan Carson



Figure 1 Two organic turnips. A picture of a non-organic turnip was both unavailable and philosophically impossible.



Of course its happening in the brain!
What other organ would it would be?



There ARE changes in brain function in functional disorders



Stress and previous trauma is a RISK FACTOR not “THE CAUSE”

Autism/ADHD

Migraine

Multiple Sclerosis

Epilepsy

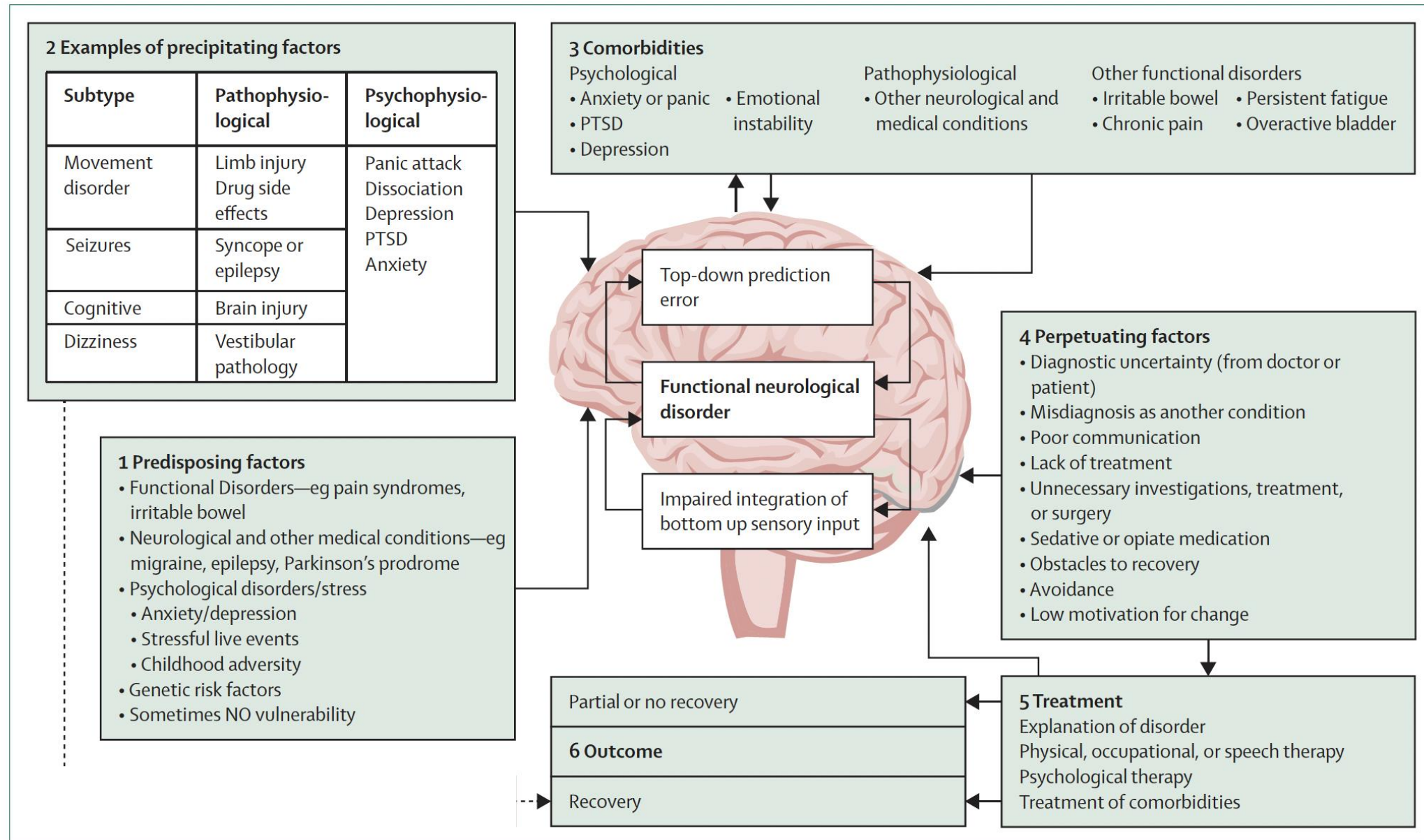
Carpal Tunnel Syndrome

Sciatica

Joint Hypermobility/EDS3

Having another neurological/medical condition
is just a strong a risk factor as Stress

FND – Aetiology and Mechanism



FND is not malingering



Mark Edwards



Mahinda Yogarajah



Jon Stone

Why functional neurological disorder is not feigning or malingering

Mark J. Edwards¹✉, Mahinda Yogarajah^{2,3,4} & Jon Stone⁵

Abstract

Functional neurological disorder (FND) is one of the commonest reasons that people seek help from a neurologist and is for many people a lifelong cause of disability and impaired quality of life. Although the evidence base regarding FND pathophysiology, treatment and service development has grown substantially in recent years, a persistent ambivalence remains amongst health professionals and others as to the veracity of symptom reporting in those with FND and whether the symptoms are not, in the end, just the same as feigned symptoms or malingering. Here, we provide our perspective on the range of evidence available, which in our view provides a clear separation between FND and feigning and malingering. We hope this will provide a further important step forward in the clinical and academic approach to people with FND, highlighting the clinical and academic importance of FND.

Sections

Introduction

Clinical and epidemiological data


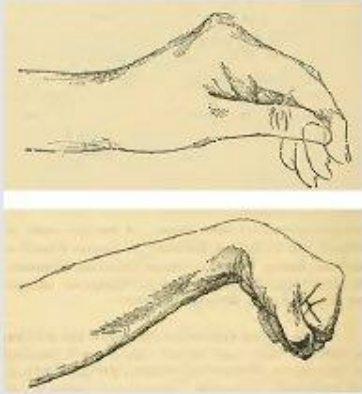






Experimental data

Models of brain function

Detection of feigning

Conclusions

Table 1 | Historical consistency of typical FND presentations

	FND presentation			
	Functional leg weakness	Functional dystonia	Functional facial dystonia	Functional seizures
Clinical features	Dragging gait with hip externally rotated	Clenched fist sometimes with wrist flexion	Orbicularis oculis contraction and contralateral raised eyebrow	'Arc-de-cerle' appearance
19th century				
21st century				

FND, functional neurological disorder. Top row of images, from left to right: reprinted from ref. ⁷⁹, reprinted from ref. ⁸⁰, reprinted from ref. ⁸¹, reprinted from ref. ⁸². Bottom row of images, from left to right: not previously published; reprinted with permission from ref. ⁸³, BMJ Publishing; adapted with permission from ref. ⁸⁴, Jon Stone; reprinted with permission from ref. ⁸⁵, Swiss Medical Forum.

Why functional neurological disorder is not feigning or malingering

Mark J. Edwards¹, Mahinda Yegorajah^{1,2} & Jon Stone³

Abstract
Functional neurological disorder (FND) is one of the commonest reasons that people seek help from a neurologist and is for many people a lifelong cause of disability and impaired quality of life. Although the evidence base regarding FND pathophysiology, treatment and service development has grown substantially in recent years, a persistent ambivalence remains amongst health professionals and others as to the veracity of symptom reporting in those with FND and whether the symptoms are not, in the end, just the same as feigned symptoms or malingering. Here, we provide our perspective on the range of evidence available, which in our view provides a clear separation between FND and feigning and malingering. We hope this will provide a further important step forward in the clinical and academic approach to people with FND, leading to improved attitudes, knowledge, treatments, care pathways and outcomes.

Sections
Introduction
Clinical and epidemiological data
Experimental data
Models of brain function
Detection of feigning
Conclusions

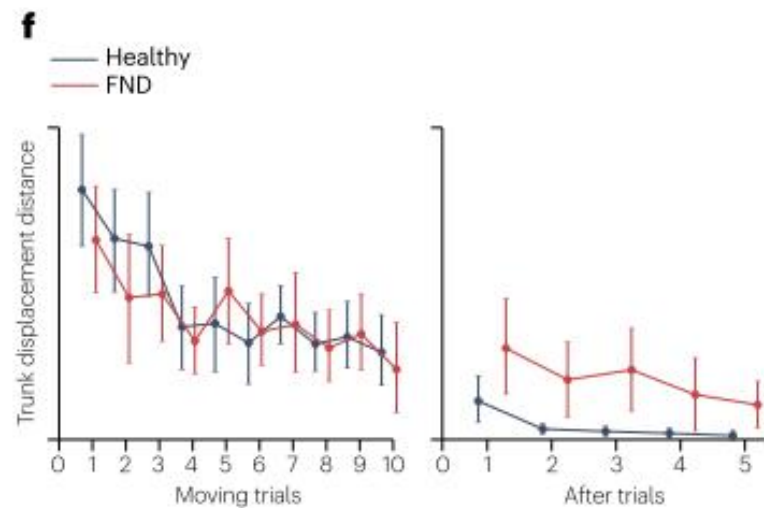
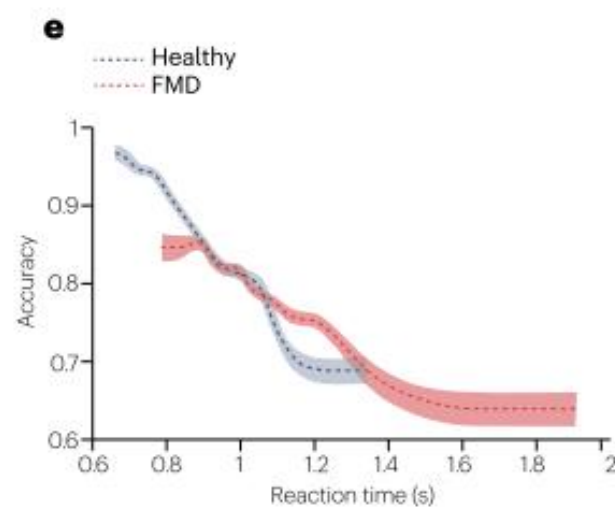
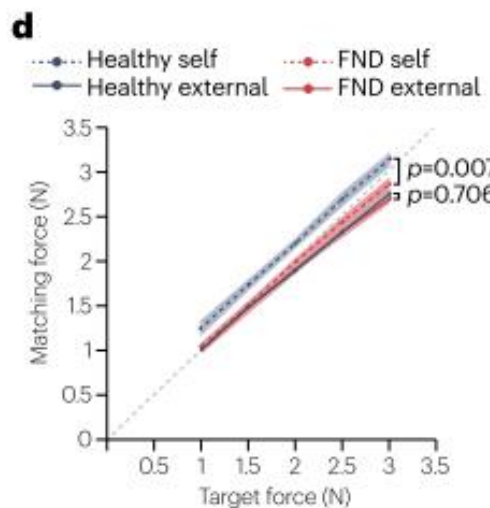
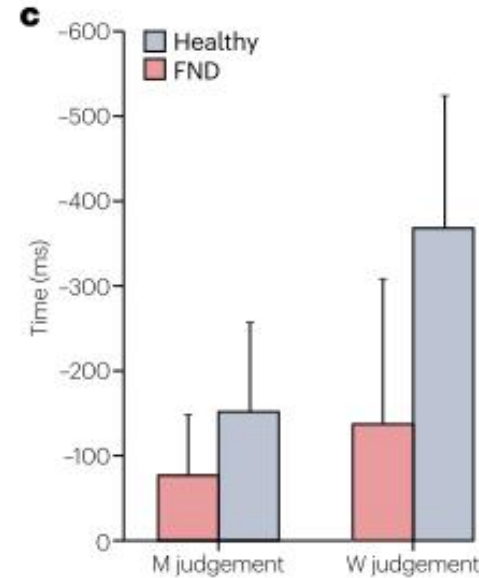
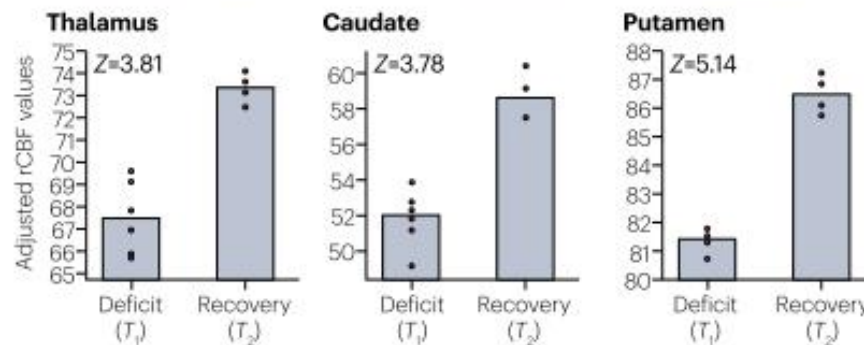
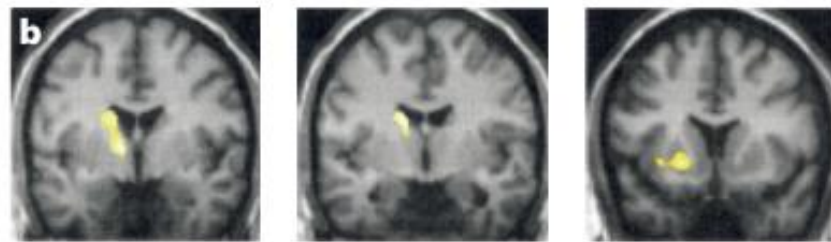
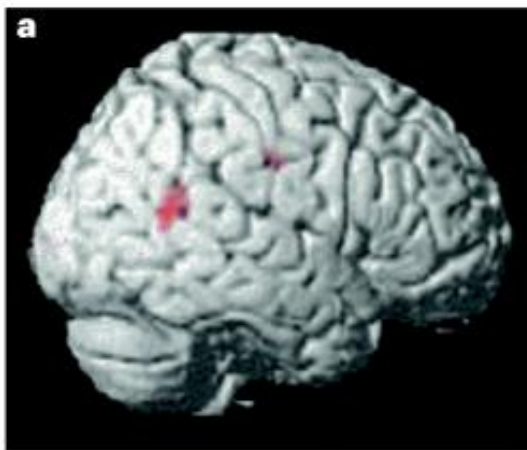


Fig. 1 | A range of functional neuroimaging and neurophysiological evidence supporting FND as a disorder distinct from feigning. a, Hypoactivation (red)

attenuation, and therefore had greater precision of force matching than healthy controls. e, A specific pattern of response indicating poor evidence accumulation

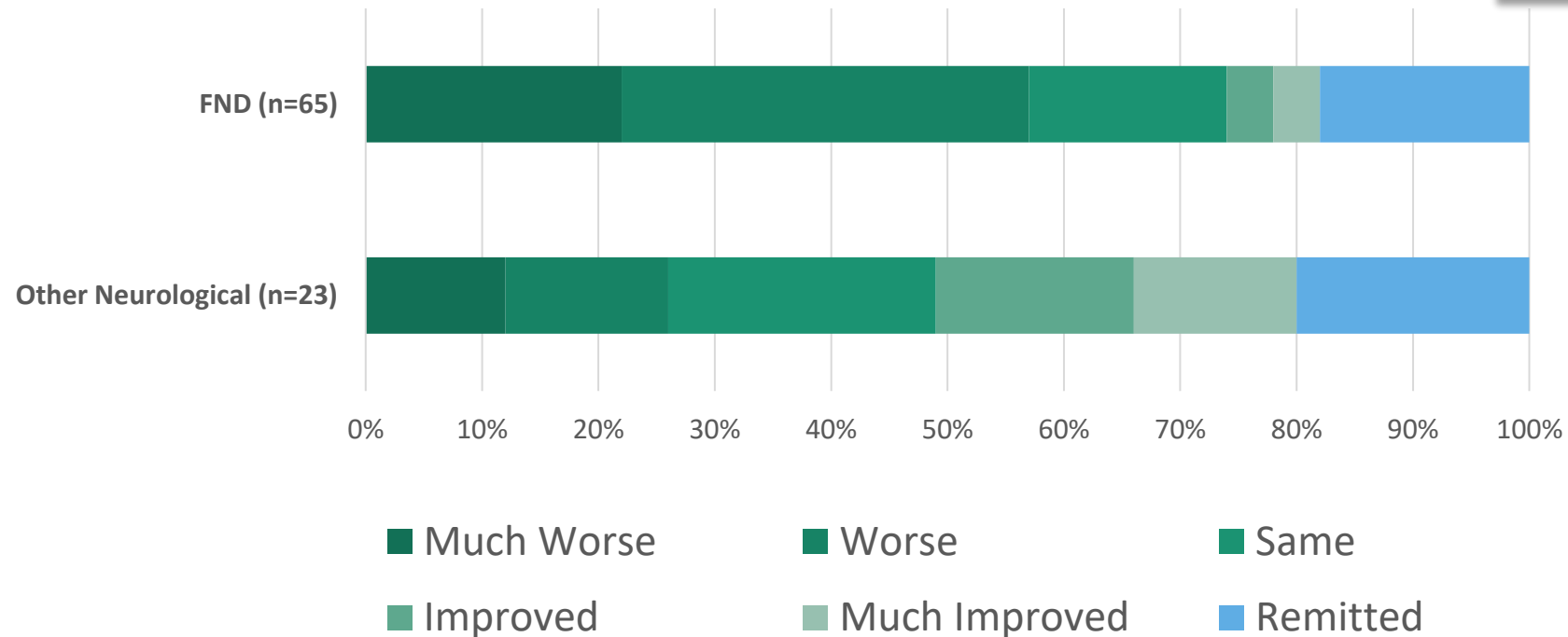
Treatment needed and can help

Functional Disorders often persist and are disabling



The prognosis of functional limb weakness: a 14-year case-control study

Jeannette M. Gelauff,^{1,2} Alan Carson,¹ Lea Ludwig,¹ Marina A. J. Tijssen² and Jon Stone¹



Neuropsychiatry

RESEARCH PAPER

The prognosis of functional (psychogenic) motor symptoms: a systematic review

Jeannette Gelauff,¹ Jon Stone,¹ Mark Edwards,³ Alan Carson²

Chapter 43

Prognosis of functional neurologic disorders

J. GELAUFF¹ AND J. STONE^{2*}

¹Department of Neurology, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands
²Department of Clinical Neurosciences, Centre for Clinical Brain Sciences, University of Edinburgh, Edinburgh, UK

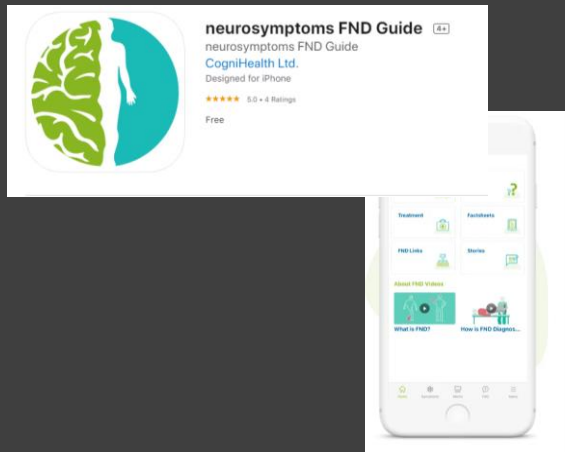
PAPER

The 12 year prognosis of unilateral functional weakness and sensory disturbance



J Stone, M Sharpe, P M Rothwell, C P Warlow


See Editorial Commentary, p. 557 J Neurol Neurosurg Psychiatry 2003;74:591-596


Knowledge can be power




neurosymptoms.org






Download FND app  

FND Links Feedback Donate Language  English

 **FND Guide**
neurosymptoms.org

Search  3 Saved Items / Recommender

Home Symptoms Causes Treatment Stories Media FAQ About Fact Sheets

 **Check out the NEW Functional Neurological Disorder (FND) Formulation Tool**     [Launch](#)

Functional Neurological Disorder (FND):

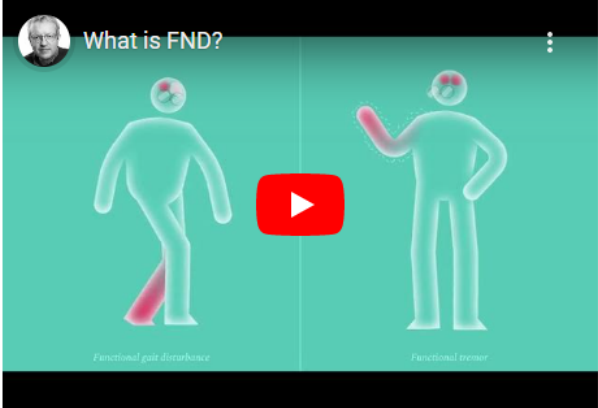
FND describes neurological symptoms like limb weakness, tremor, numbness or blackouts, related to the movement and sensation parts of the nervous system.....

- ✓ Caused by a **PROBLEM** with the **FUNCTIONING** of the nervous system
- ✓ A “software” issue of the brain, not the hardware (as in stroke or MS)
- ✓ With positive diagnostic features typical of FND
- ✓ Cause day to day difficulties for the person who experiences them



Functional Neurological Symptoms are:

Troublesome symptoms that someone wishes to understand without necessarily having a ‘disorder’ are called functional neurological symptoms, and this site is for you too.

FND and functional neurological symptoms are surprisingly common but can be difficult for patients and health professionals to understand.



Download FND app

FND formulator

neurosymptoms.org

FND Guide
neurosymptoms.org

Hello there, I am your FND digital health. I recommend that you start activities whenever you want. Please visit neurosymptoms.org.

Welcome to the FND Fo

Who is this for? If you are living with FND (Functional Disorder) or are a healthcare professional supporting someone with FND, you have come to the right place!

- ✓ Help you make sense of your symptoms
- ✓ Understand which of your conditions are functional
- ✓ Think through potential causes and triggers
- ✓ Prepare for your healthcare appointment
- ✓ Communicate better with your healthcare professional

What can you expect? When you go through all the information you have shared, you will be presented with a report of the answers you have shared along the way. You can share your report in many ways:

- ✓ Use it as a way to keep track of how your symptoms change over time by revisiting the activities you have shared
- ✓ Share it with your healthcare professional so they can understand you better

My FND Formulation Report

TIME: 10:53 PM
DATE: 27 Oct, 2022

My Symptoms

Symptom	Severity
Blackouts or Seizures	Bothered a lot
Falls/Drop attacks	Bothered a lot
Sensitivity to light, sound or movement	Bothered a little
Diarrhoea	Bothered a little
Headache/Migraine	Bothered a lot
Tics	Bothered a little
Walking / Balance problems	Bothered a little
Spaced out / Disconnected	Bothered a lot
Speech problems	Bothered a little
Memory or Concentration problems	Bothered a little
Leg Pain	Bothered a little
Sleep Problems	Bothered a little
Fatigue	Bothered a lot
Anxiety, Worry or Distress	Bothered a little

● Not at all bothered ● Bothered a little ● Bothered a lot

My quality of life

Area	Problem Level
Mobility	I have severe problems in walking about
Usual Activities	I have moderate problems doing my usual activities
Anxiety/Depression	I am slightly anxious or depressed
Self-Care	I have moderate problems washing or dressing myself
Pain/Discomfort	I have moderate pain or discomfort

Notes

My life has completely changed since I developed FND. I was a confident active person and now these symptoms are really dominating my life

“Here’s some videos you might want to watch.....”

Visit previous version of website <http://old.neurosymptoms.org> [FND Links](#) [Feedback](#) [Donate](#) [Language](#) English (UK)

FND Guide
neurosymptoms.org


Search 3 Saved Items / Recommender

[Home](#) [Symptoms](#) [Causes](#) [Treatment](#) [Stories](#) [Media](#) [FAQ](#) [About](#) [Fact Sheets](#)

[Home](#) / [Media](#) / [FND videos](#)


FND videos

J What is FND?




What is FND?
[Read More >>](#)

J How is FND diagnosed




How is FND Diagnosed
[Read More >>](#)

J Can you have FND and othe...




Can you have FND and another neurological condition?
[Read More >>](#)

J How is FND treated?




How is FND treated?

J What causes FND?



What causes FND?

J Functional Neurological Dis...



Functional Neurological Dis...

“Theres an app.....”



Store

Mac

iPad

iPhone

Watch

TV

Music

Support



App Store Preview

Open the Mac App Store to buy and download apps.



neurosymptoms FND Guide 4+

neurosymptoms FND Guide

[CogniHealth Ltd.](#)

Designed for iPhone

★★★★★ 5.0 • 4 Ratings

Free

iPhone Screenshots

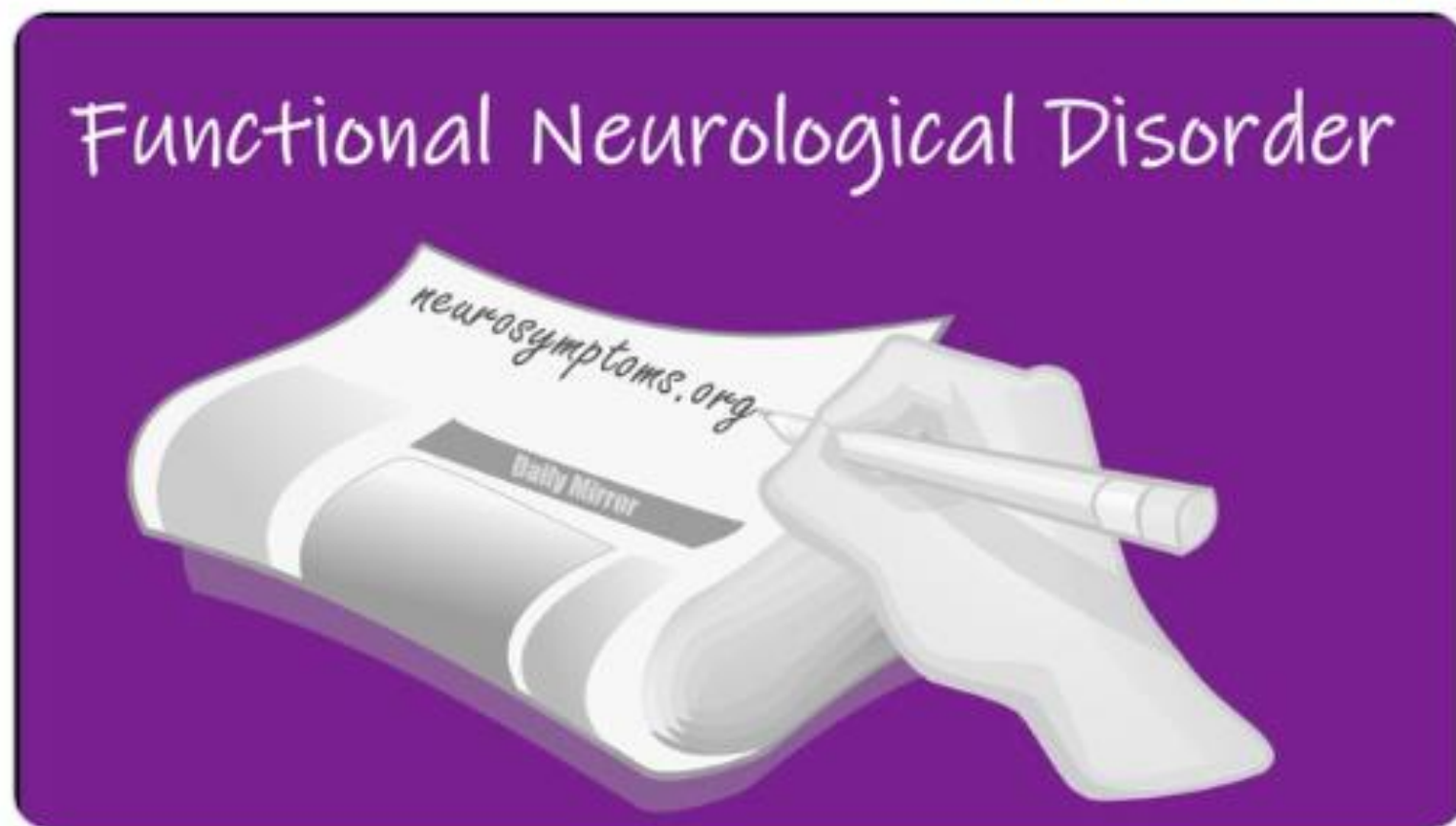




FND Action @FNDAction · May 4




This is what many doctors see as the only treatment needed for those diagnosed with a Functional Neurological Disorder [#FND](#) [#NEAD](#) [#action4FND](#)



Information – welcomed by patients but doesn't alter outcome

SHARE July 20, 2020 NULL HYPOTHESIS

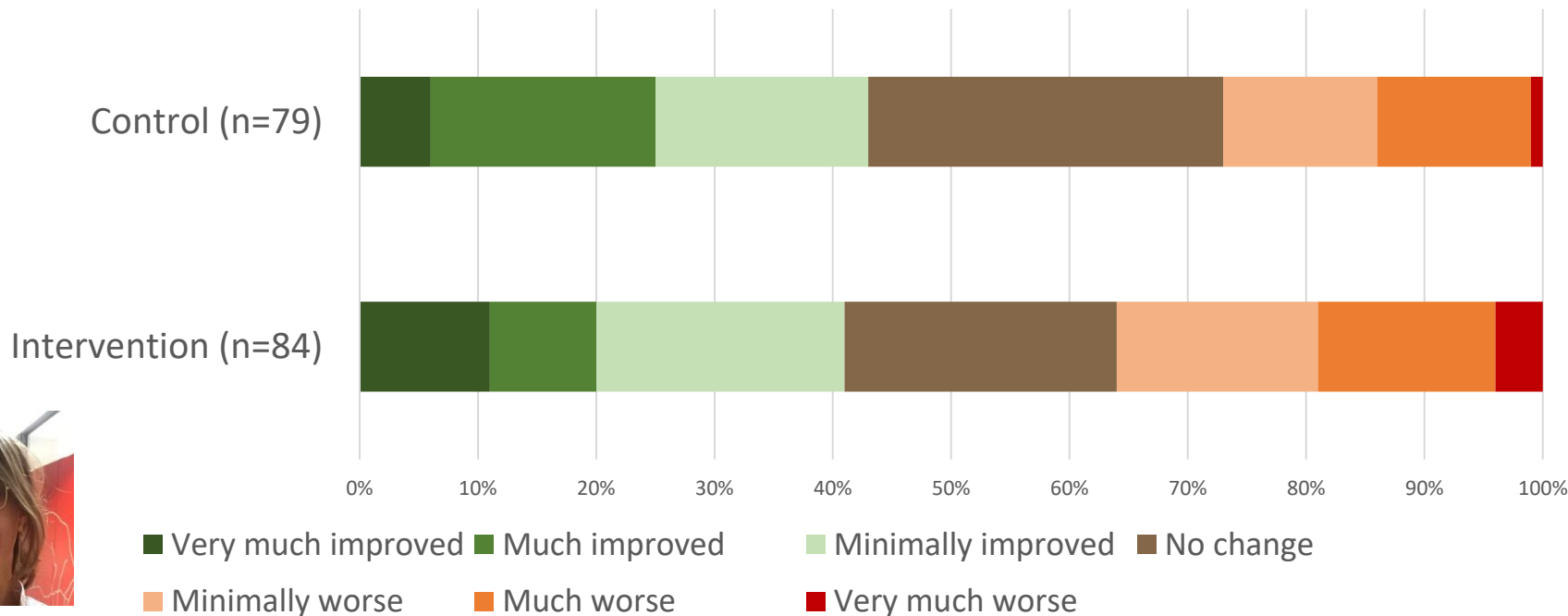
Internet based self-help randomized trial for motor Functional Neurological Disorder (SHIFT).

Jeannette M. Gelauff, Judith G. Rosmalen, Alan Carson,  Joke M. Dijk, Martijn Ekkel, Glenn Nielsen, Jon Stone, Marina A.J. Tijssen

First published July 20, 2020, DOI: <https://doi.org/10.1212/WNL.00000000000010381>

Neurology®

Self-rated general health at 6 months (CGI)



Dr Jeannette Gelauff

Treatment recommendations for FND

Research

Physiotherapy for functional motor disorders: a consensus recommendation (Long Version)

Glenn Nielsen,^{1,2} Jon Stone,³ Audrey Matthews,⁴ Melanie Brown,⁴ Chris Sparkes,⁵ Ross Farmer,⁶ Lindsay Masterton,⁷ Linsey Duncan,⁷ Alisa Winters,³ Laura Daniell,³ Carrie Lumsden,⁸ Alan Carson,⁹ Anthony S. David,¹⁰ Mark Edwards¹

Occasional essay

Occupational Therapy Consensus Recommendations for Functional Neurological Disorder (Long Version)

Clare Nicholson,¹ Mark J Edwards,² Alan Carson,³ Paula Gardiner,⁴ Dawn Golder,⁵ Kate Hayward,¹ Susan Humblestone,⁶ Helen Jinadu,⁷ Carrie Lumsden,⁸ Julie MacLean,⁹ Lynne Main,¹⁰ Lindsey McGregor,¹¹ Glenn Nielsen,² Louise Oakley,¹² Jason Price,¹³ Jessica Ranford,⁹ Jasbir Ranu,¹ Ed Sum,¹⁴ Jon Stone³

General neurology

Review

Management of functional communication, swallowing, cough and related disorders: consensus recommendations for speech and language therapy

Janet Baker,^{1,2} Caroline Barnett,³ Lesley Cavalli,^{4,5} Maria Dietrich,⁶ Lorna Dixon,⁷ Joseph R Duffy,⁸ Annie Elias,⁹ Diane E Fraser,¹⁰ Jennifer L Freeburn,¹¹ Catherine Gregory,² Kirsty McKenzie,¹² Nick Miller,¹³ Jo Patterson,¹⁴ Carole Roth,¹⁵ Nelson Roy,^{16,17} Jennifer Short,¹⁸ Rene Utianski ,^{19,20} Miriam van Mersbergen,²¹ Anne Vertigan,^{22,23} Alan Carson,²⁴ Jon Stone ,²⁴ Laura McWhirter ²⁴

Review

Systematic review of psychotherapy for adults with functional neurological disorder

Myles Gutkin ,^{1,2} Loyola McLean ,^{3,4} Richard Brown ,^{5,6} Richard A Kanaan ¹

Physiotherapy for functional disorders



Psychological Therapy for Functional Disorders



Dr Kinjal Goyal
Pune, India

Occupational Therapy for Functional Disorders



Clare Nicholson
London

Speech Therapy for Functional Disorders



Jan Baker,
Australia

Treating Pain and other comorbidities

The screenshot shows a website interface with a sidebar on the left and a main content area. The sidebar includes the FND G neurosympto logo, navigation links for Home and Symp, a breadcrumb trail Home / Media / Pain, a section for Pain Video, and a paragraph of text: "Pain is NOT define Chronic Pain share scan. These videos problem." Below this is a small video thumbnail. The main content area features a large video player with the title "Tame the Beast" and subtitle "It's time to rethink persistent pain". The video player includes "Watch later" and "Share" buttons, a red play button, and a "Watch on YouTube" button. Below the video player, there is a caption: "From tamethebeast.org. This is another great video from Lorimer Moseley – a pain researcher and clinician in". At the bottom of the page, there are three "Read more >>" links.

FND G neurosympto

Home Symp

Home / Media / Pain

Pain Video

Pain is NOT define
Chronic Pain share scan. These videos problem.

Tame Th
Tam
It's tim

Tame the Beast

Read more >>

Read more >>

Read more >>

Tame the Beast – It's time to rethink persistent pain

Watch later Share

Tame the Beast
It's time to rethink persistent pain

Watch on YouTube

From tamethebeast.org. This is another great video from Lorimer Moseley – a pain researcher and clinician in

Other resources



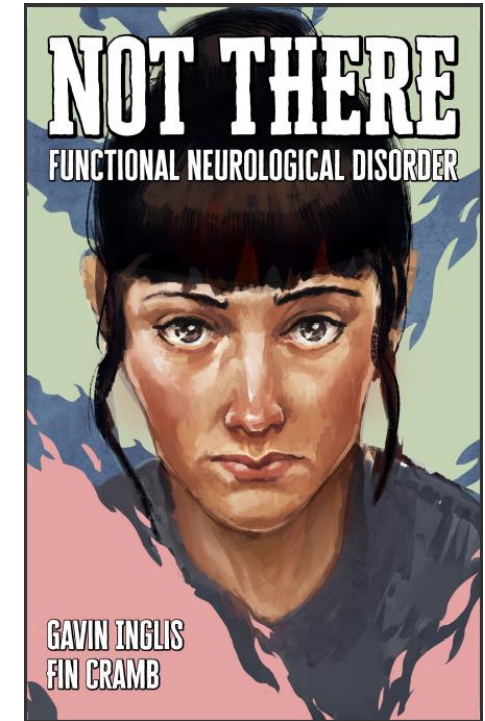
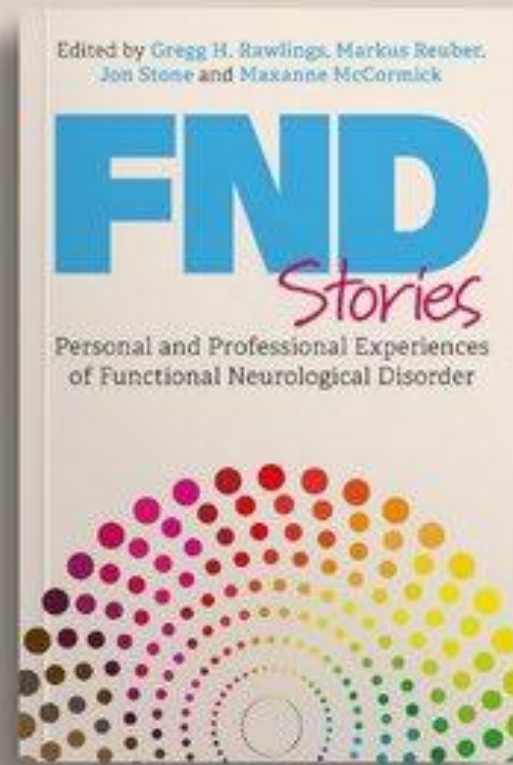
Dr Chris Symeon
@chris_sym

Excited to be launching a new app today! @MyFNDapp

It has has been a long journey but I am really proud of the result. Thank you to everyone who supported it.
#fndaware #FND



2:54 PM · Jun 9, 2020 · Twitter Web App



FND research in the 2020s

Its common
and disabling

FND diagnosis
reliable as
others

Diagnosis of
Inclusion

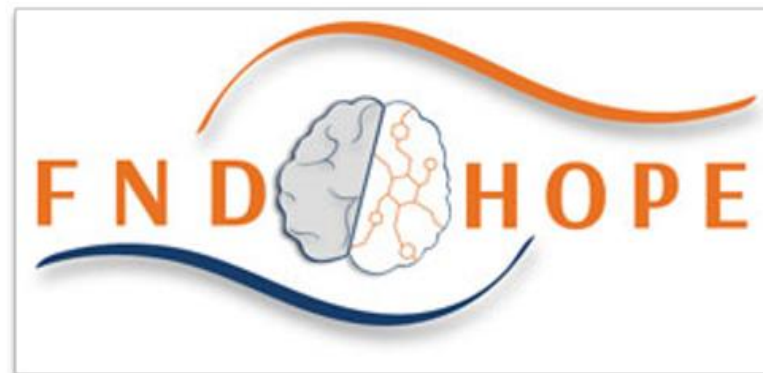
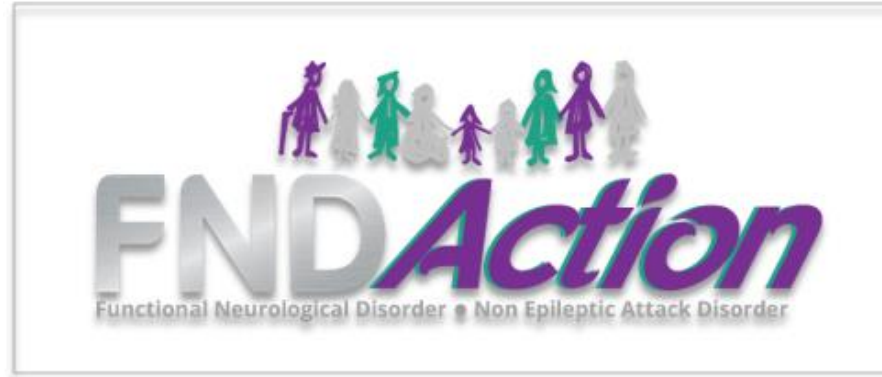
Psychiatric
and
Neurological

Patients rarely
malingering

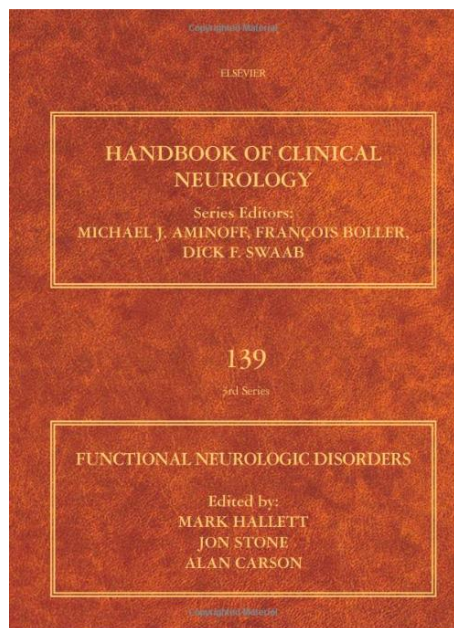
Treatment
needed and
can help

The future of FND

Patient led organisations and advocates for FND for the first time

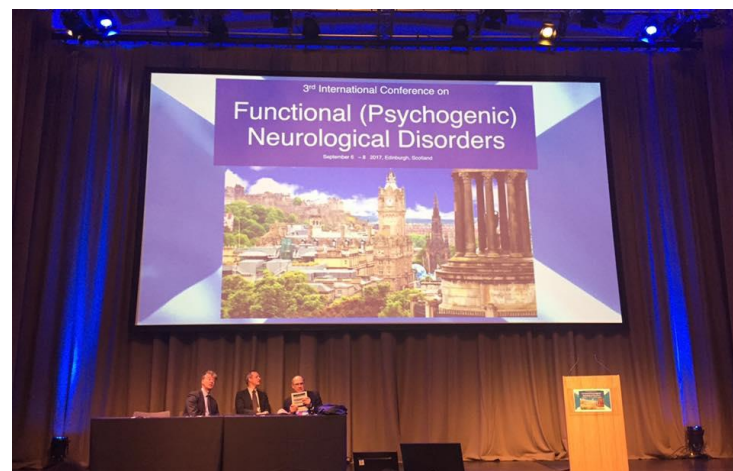


The FND Society and international networks



2016

51 chapters covering FND
Ed. Hallett, Stone, Carson



2017

FND meeting in Edinburgh
550 delegates



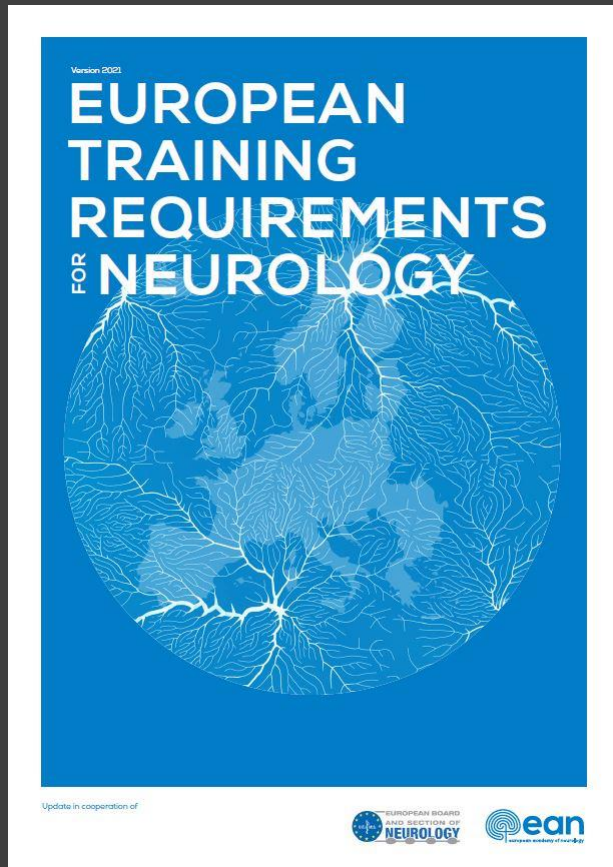
2022

FND Society meeting in
Boston
1000+ delegates

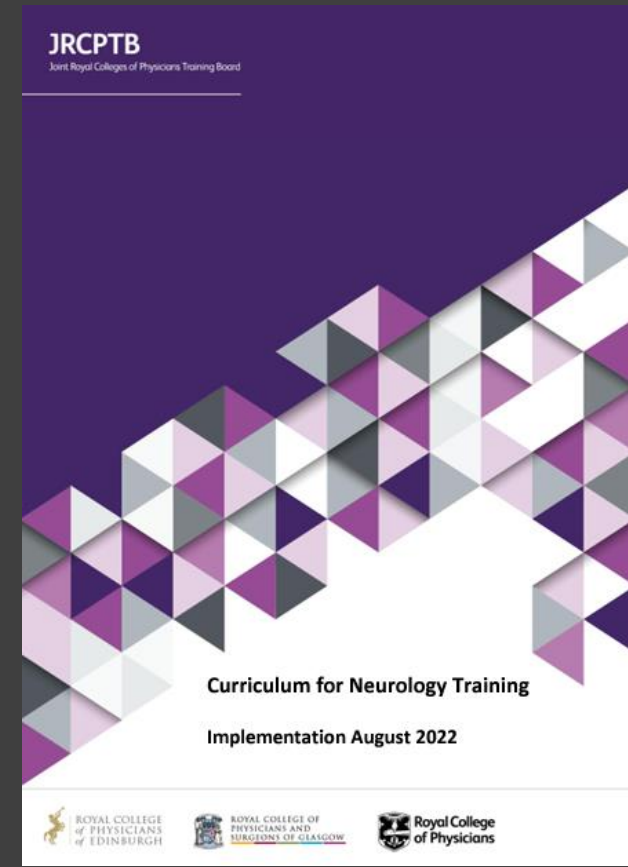


FUNCTIONAL
NEUROLOGICAL
DISORDER
SOCIETY

FND now a mainstream condition in UK
neurology – improving in other countries



EU -FND one of
17 core topics
2021



UK -FND one of
8 core topics
2022



Jon Stone

@jonstoneneuro

Promote



Thanks [@theJeremyVine](#) for featuring FND on BBC Radio 2 today for a national UK audience.

Glad there were so many voices of people with FND including [@Zoecoles07](#) [@TomPlender](#) and the two callers. FND at 1.05.



From [bbc.co.uk](#)

3:03 PM · Mar 19, 2024 · 5,247 Views

View post engagements



9



25



110



7



Jeremy Vine show
Radio 2 – last
Tuesday



8-11 June 2024
Verona, Italy

FUNCTIONAL
NEUROLOGICAL
DISORDER
SOCIETY
fndsociety.org

5th International Conference on Functional Neurological Disorder

Virtual CME Course

[Functional Neurological Disorder: Putting Principles into Practice](#)

[Register Today](#)

Membership



JOIN US

Because the FND picture needs you



Joining FND Society means being part of a

News and Events

New FNDS Resource Library (members only)

Diagnosis of Functional Dystonia Webinar - Register Today!



Fnd Portal

Jun 5 · 48 min read · [Listen](#)



Cadenza for Fractured Consciousness: A Personal History of the World's Most Misunderstood Illness



FND and Women's Health Study – Thank you

FND and Women's Health We need you!

We have TWO surveys exploring:

- 1) Pregnancy and FND and
- 2) Women's health and FND

For any woman aged over 18 with FND

FND Pregnancy/Womens Health Collaboration

[Click here for link to survey.](#)

Chief Investigator: Alex Lehn . Ethics approvals (HREC/2023/MNHA/99899 and HREC/2022/QMS/89227).
More information at FND.Research@health.qld.gov.au.



https://fndaustralia.com.au/research/womens_health.html

Diagnosing FND with a brain scan

NeuroImage: Clinical 35 (2022) 103090

Contents lists available at [ScienceDirect](https://www.sciencedirect.com)

NeuroImage: Clinical

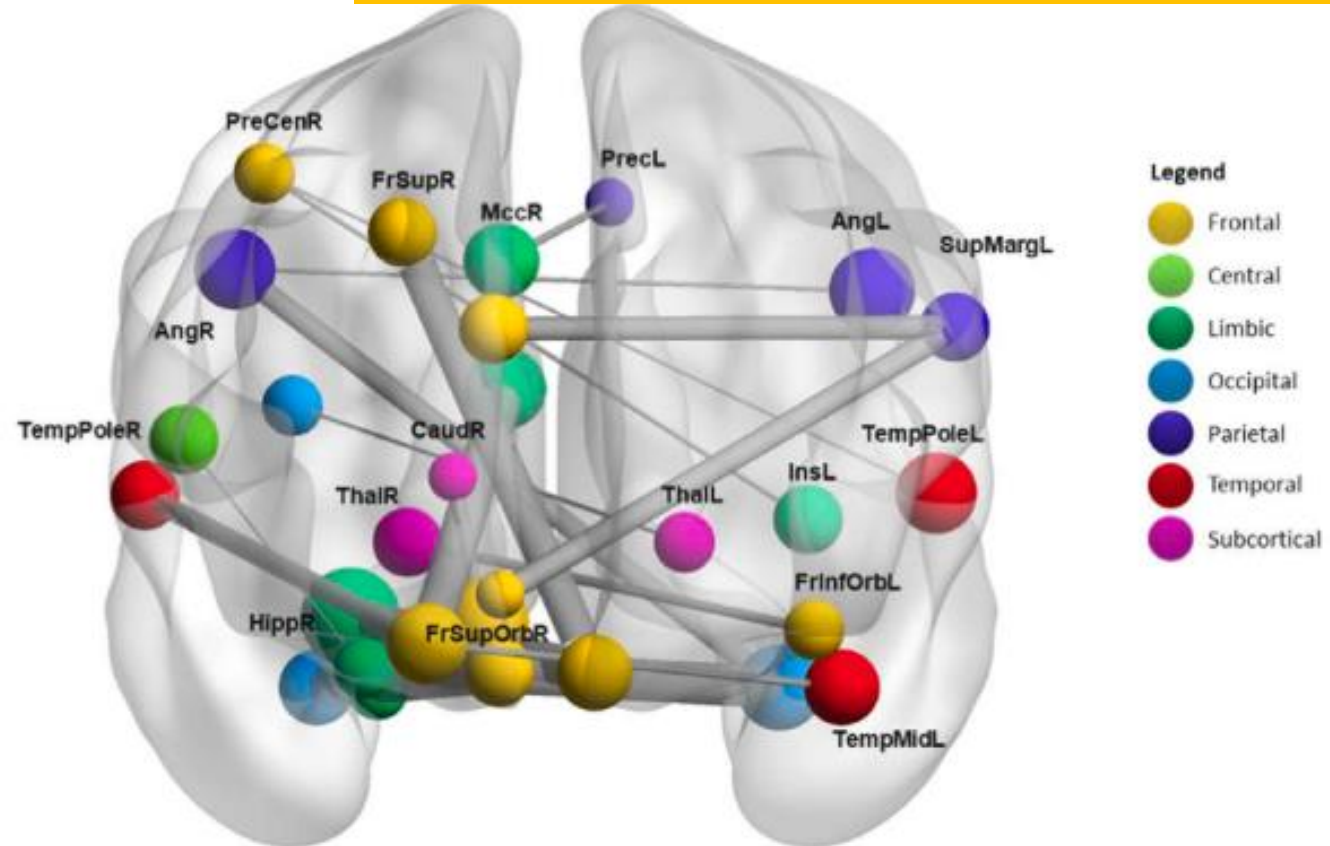
journal homepage: www.elsevier.com/locate/ynicl



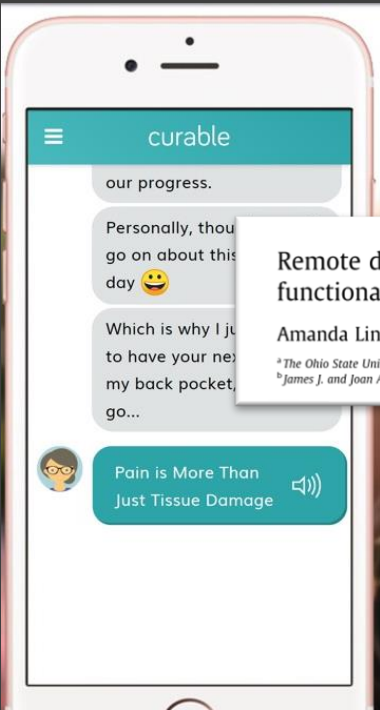
72% accuracy detecting FND vs healthy controls from resting state fMRI (functional brain imaging) alone

Multi-centre classification of functional neurolog:
resting-state functional connectivity

Samantha Weber^a, Salome Heim^a, Jonas Richiardi^b, Dimitri V Tereza Serranová^c, Robert Jech^{e,f}, Ramesh S. Marapin^{g,h}, Ma Selma Aybek^{a,*}



New Treatments for FND



Remote delivery of cognitive behavioral therapy to patients with functional neurological disorders: Promise and challenges

Amanda Lin^{a,*}, Alberto J. Espay^b

^aThe Ohio State University Wexner Medical Center, 410 W 10th Ave, Columbus, OH 43210, United States

^bJames J. and Joan A. Gardner Family Center for Parkinson's Disease and Movement Disorders, Department of Neurology, University of Cincinnati, Cincinnati, OH, United States



Trial Of Neurostimulation In Conversion Symptoms (TONICS): a feasibility randomised controlled trial of transcranial magnetic stimulation for functional limb weakness

Original research

Susannah Pick¹, John Hodsoll¹, Biba Stanton^{1,2}, Amy Eskander², Ioannis Stavropoulos³, Kiran Samra², Julia Bottini², Hena Ahmad², Anthony S David⁴, Alistair Purves³, Timothy R Nicholson¹



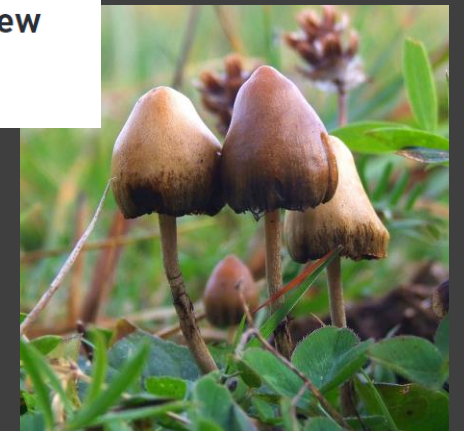
Virtual Reality-Delivered Mirror Visual Feedback and Exposure Therapy for FND: A Midpoint Report of a Randomized Controlled Feasibility Study

Kim Bullock, M.D., Andrea Stevenson Won, Ph.D., Jeremy Bailenson, Ph.D., Raquel Friedman, Psy.D.



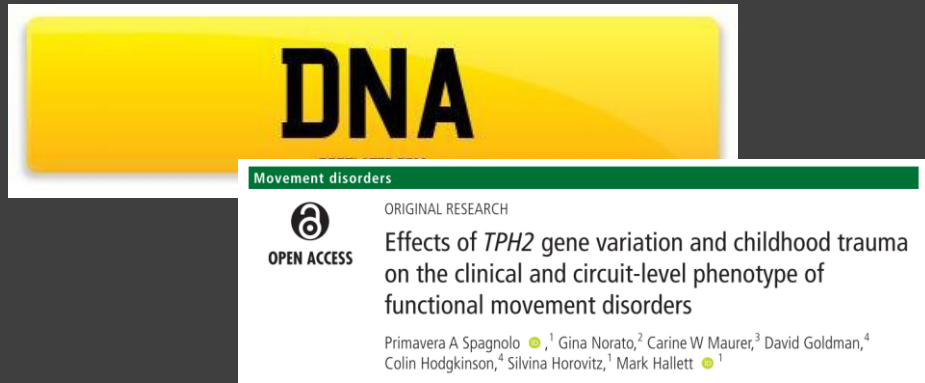
Psychedelic treatment of functional neurological disorder: a systematic review

Matthew Butler¹, Mathieu Seynaeve, Timothy R. Nicholson, Susannah Pick, Richard A. Kanaan, Andrew Lees, Allan H. Young² and James Rucker¹

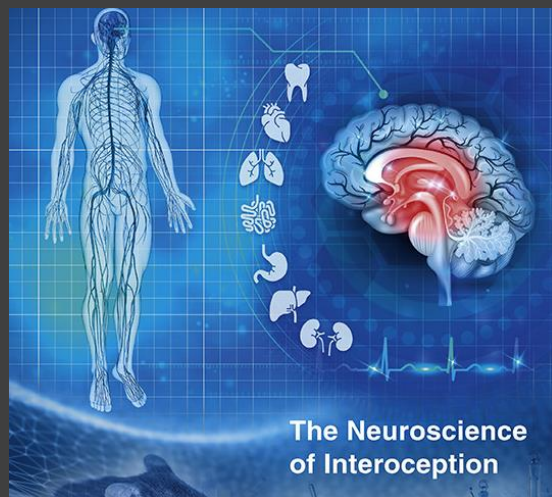


New research on causes of FND

Genetics



Interoception



Autism Spectrum/ ADHD/

Joint Hypermobility

Autonomic dysfunction

Immune Dysregulation

I can't find anyone
to help..

Im on a 12 month
waiting list

Ive had upsetting
experiences with
health
professionals

Ive done
everything and still
things aren't better



The University of Edinburgh
Edinburgh Neuroscience

FND Research Group, Edinburgh



CORE
LIBRARY
for FND



@jonstoneuro on
Twitter/X



FND Research Group

Centre for Clinical Brain Sciences, University of



Jon Stone
Neurology

Laura McWhirter
Neuropsychiatry

Alan Carson
Neuropsychiatry

Ingrid Hoeritzauer
Neurology

FRG – Other current members



Caoimhe
McLoughlin
Psychiatry



Veronica
Cabreira
Neurology



Sarah
McRae
Physio

Jon.Stone@ed.ac.uk

Twitter: @jonstoneuro

**CORE
LIBRARY
for FND**



Alumni and ongoing Collaborators



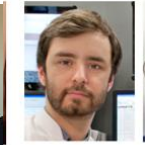
Alex Lehn²
Neurology
iBook



Lea Ludwig³
Psychology
CODES



Paula
Gardiner
CBT/Physio



Stoyan
Popkirov
Trauma CRPS
PPPD Cognition



Sara
Finkelstein
Neurology



Tommaso
Ercoli
Neurology



Hannah
Callaghan
CODES



Jeannette
Gelauff
Neurology



Clare Diamond
Physio4FMD

Thank you !

jon.stone@ed.ac.uk
twitter - @jonstoneneuro