



# FND Research 2021 and 2022 REPORT



The University of Edinburgh

Edinburgh Neuroscience



**CCBS**

Centre for Clinical Brain Sciences



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# TABLE OF CONTENTS

TO OUR SUPPORTERS - THANK YOU! _____	3
OUR TEAM _____	5
2021 and 2022 HIGHLIGHTS _____	6
Functional Cognitive Disorders _____	6
Functional Speech and Swallowing disorders _____	7
Trial Updates _____	7
Cauda Equina Syndrome - Scan Negative, and Scan Positive _____	8
Neurosymptoms FND guide - upgrade and App _____	9
FND Society Update _____	10
FRG HALL OF FAME 2021-2022 _____	11
Other NEWS _____	12
• Working with FND Patient organisations and advocates _____	12
• Research Publications _____	12
• Media appearances. _____	12
• FND Awareness _____	13
• Ukraine. _____	13
OUR INSTITUTIONAL FUNDERS _____	14
OUR RESEARCH PUBLICATIONS 2021-2022 _____	15

# TO OUR SUPPORTERS – THANK YOU!

This is the second time we have prepared a report from our FND research group at the University of Edinburgh. research group, mainly to thank our financial supporters, explain how we are using donations and also celebrate the hard work of our team.

Many individuals have been generous to us through the University of Edinburgh and especially through the Donate link of the [neurosymptoms.org](https://neurosymptoms.org) website, which is one of the main projects that benefits from everyone's generosity

We particularly wanted to thank Jillian and Ron Eather who have continued to be so generous in supporting us.

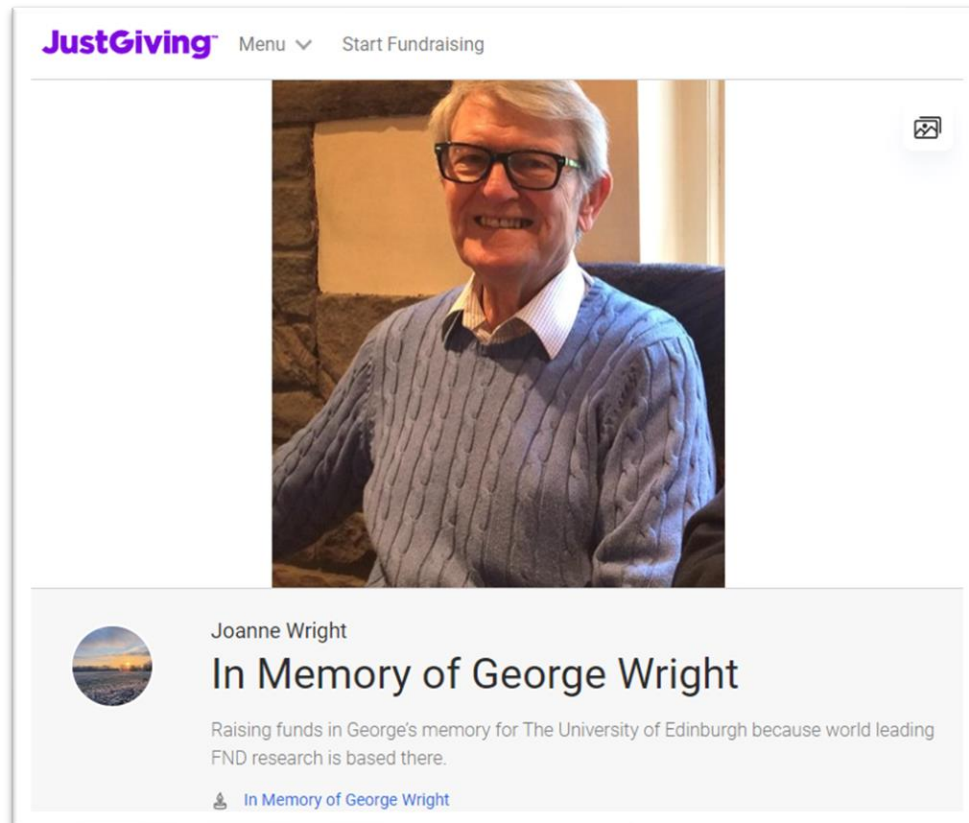
Special thanks as well to the Bellany Family and Thorntree Lodge who raised an incredible £8,150 in memory of Kirsten Bellany. Here we are accepting a cheque from Kirsten's partner and Thorntree Lodge back in July 2022 at the [Anne Rowling Clinic](#) in Edinburgh.

## The Bellany Family & Thorntree Lodge (1038) donate £8,150



to further FND research, in loving memory of Kirsten.

Most recently we are immensely honoured that George Wright who sadly died very recently chose to encourage donations to our research group instead of additional flowers at his funeral. We want to thank George, his family and his friends for this amazing gesture. At the time of this reports publication in December 2022 the link is still active if you want to donate - <https://www.justgiving.com/fundraising/FNDRResearch>



Money raised by supporters of FRG is always carefully kept for anything that we think has **direct patient benefit**. We don't spend the money on conference fees or travel for the group. Things we have spent the money on - and plan to in the future include

- Maintenance and development of the free neurosymptoms.org website and app
- Future plans to develop a research database and personalized 'pre-treatment' for people with FND on the app.
- Paying for website fees and video upgrades for the headinjurysymptoms.org site.
- Software licenses to allow data analysis.
- Video and animations to help educate patients and health professionals about FND
- A device to help 'measure' positive FND signs - to improve diagnosis and research.
- Digital material for an anti-stigma FND campaign part of a new stigma project.

# OUR TEAM



The University of Edinburgh  
Edinburgh Neuroscience

## FND Research Group

Centre for Clinical Brain Sciences, University of Edinburgh





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


**Alumni and ongoing Collaborators**



Alex Lehm<sup>2</sup>  
Neurology  
iBook



Lea Ludwig<sup>3</sup>  
Psychology  
CODES



Paula  
Gardiner  
CBT/Physio



Shyam  
Prasad  
Trauma CRPS  
PPPD Cognition



Sara  
Finkelstein  
Neurology



Tommaso  
Ercoli  
Neurology



Hannah  
Callaghan  
CODES



Jeannette  
Gelauff  
Neurology



Clare Diamond  
Physio4FND

We have an amazing multidisciplinary team, group of alumni and ongoing collaborators internationally with whom we share research ideas, all towards improving knowledge and care for people with FND.

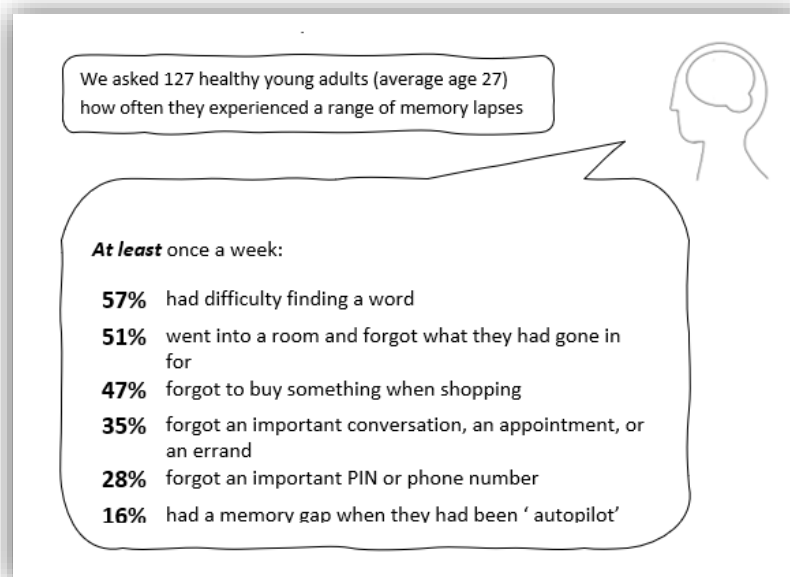
Over the last two years our four principals, Jon Stone, Laura McWhirter, Alan Carson and Ingrid Hoeritzauer have been busy on many different projects with help from new and old members of the group.

We also benefit from the work of many junior doctors including Karina Bennet, Lois de Boisanger and medical students including Dennis Walzl, Heather Smyth, Isobel Mason, Fintan Milligan and Max Fend.

# 2021 AND 2022 HIGHLIGHTS

## Functional Cognitive Disorders

Laura McWhirter continued to lead important and clinically practical research on Functional Cognitive Disorder. Laura's papers included data from her PhD looking at [improving diagnosis](#) of Functional Cognitive Disorder, a study of how common cognitive lapses are in healthy young adults (common!), a study of how different people interpret the words 'brain fog' online and a [review](#) in Practical Neurology. Laura has received many invitations to speak on this area from around the world including the UK [Association of British Neurologists](#). Our Functional Cognitive Disorder [factsheet](#), written with Biba Stanton at Kings, London is on neurosymptoms to help people understand this information. Our group is now working with colleagues in the US and Veronica Cabreira on developing better recognition and treatment of FCD.



## Covid-19 and Long Covid

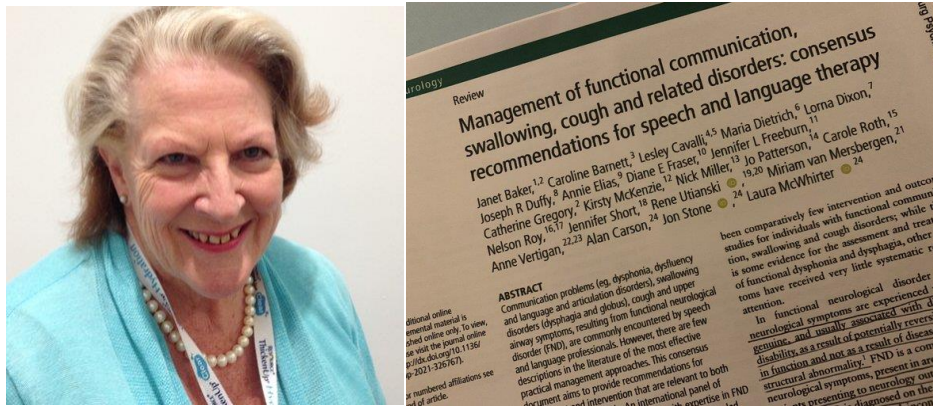
Alan and Laura recruited patients for a study funded by the Chief Scientist Office on cognitive symptoms after Covid-19 infection. They co-authored papers and appeared on [BBC Panorama](#) and [ITV national news](#) on this topic where there is much emerging new data. Their study has completed recruitment and will report in future.



## Functional Speech and Swallowing disorders

Laura McWhirter also celebrated the completion of a huge piece of work in 2021 with the publication of our [consensus recommendation](#) on the diagnosis and treatment of FND related speech and swallowing problems. This paper, which is a companion to others the group have been involved with for Physiotherapy and Occupational Therapy in FND, brought together an international authorship of 22 mainly Speech and Language Therapists (SLTs) led by the wonderful Jan Baker in Sydney.

What we noticed was that it was really hard for SLTs to find out about practical ways in which they could approach treatment for their patients with FND. As a result we were often told that patients didn't get treatment at all. We wrote this for non-specialist SLTs to gain more confidence in treatment, and as a basis for future therapy trials. We were also thrilled when this sparked a study day for SLTs organized by the Royal College of SLT in March 2022 - the recording is still available for FNDs members



Jan Baker

## Trial Updates

### Physio4FMD trial

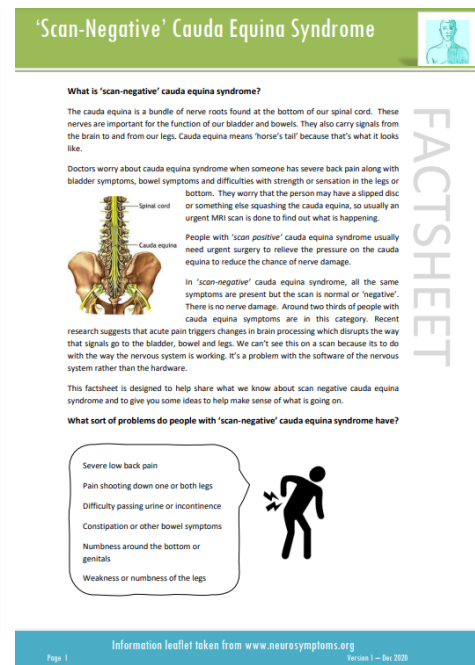
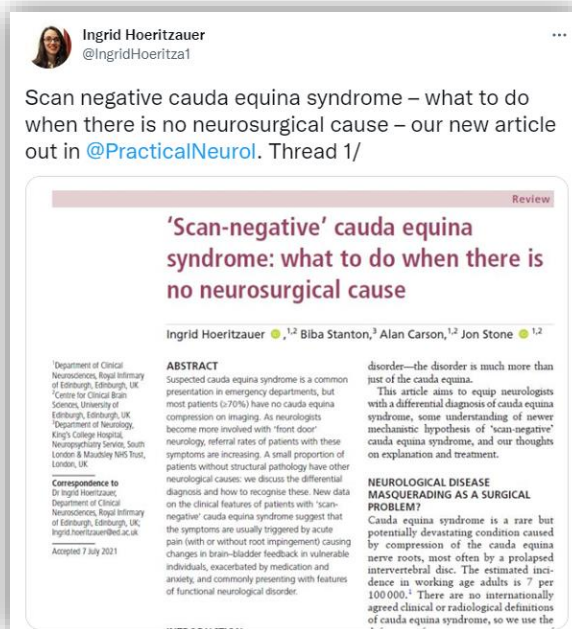
- Funded by NIHR, UK, and led by Glenn Nielsen at St Georges Hospital University, London this will be by far the largest physiotherapy treatment trial for FND.
- Recruitment had to pause during the pandemic, but we were able to restart, in Edinburgh with thanks to Sarah McRae, our new neurophysio team member.
- We reached the target recruitment of over 350 and results should be available later in 2023 or 2024
- We also said goodbye and thank you to Clare Diamond- our Physio4FMD research worker in August. We were delighted that she got a promotion to another trials setting in Bristol.

## CODES trial

- The [CODES trial](#) for functional seizures, led by Laura Goldstein reported in In May 2020 in Lancet Psychiatry. This was the largest ever treatment trial in FND and again FRG were co-investigators. Edinburgh was the largest recruiter.
- Over 2021 and 2022 more publications have emerged from the CODES trial including data from 6 months outcome, and data looking at which factors helped explain improvement.

## Cauda Equina Syndrome – Scan Negative, and Scan Positive

Ingrid Hoeritzauer continued her work on Cauda equina symptoms - that is people presenting (usually to neurosurgeons) who can't pee, often with back pain and weak legs. Ingrid's work, with others, has shown that up to 80% of people with these presentations don't have structural abnormalities that fully explain what's happening, and many of them have FND. Her review article in Practical Neurology went viral among orthopaedic and spinal surgeons - a sign that they were aware how common and understudied this issue is - and broke FRG records for a [tweet](#) with over quarter of a million views in August 2021. New [factsheet](#) too! Ingrid and Jon are delighted to be serving on the medical board of [Fowlers Syndrome UK](#) and collaborating on future chronic urinary retention research.



Ingrid also was senior author on the largest ever study of 621 people with scan 'positive' cauda equina syndrome [in Lancet Global health](#).

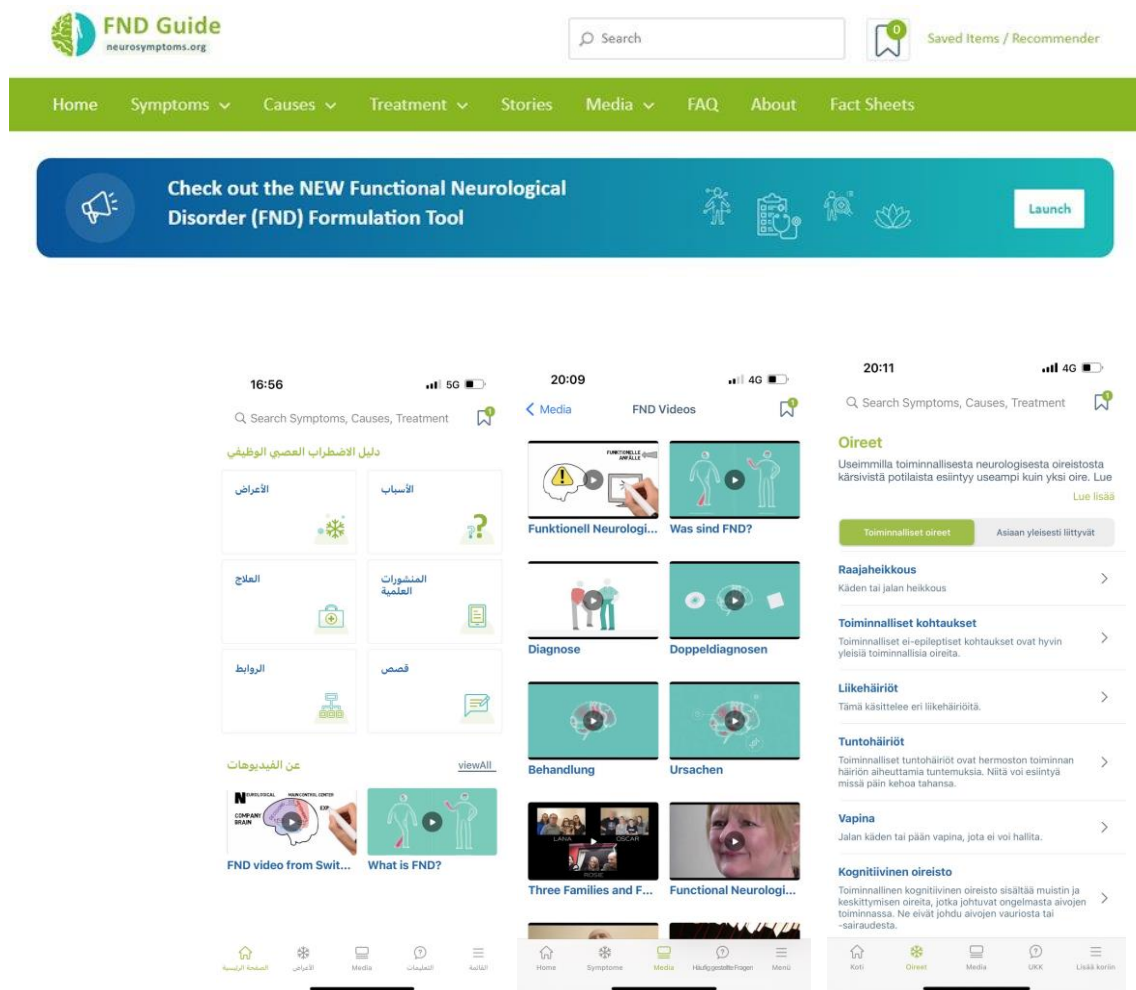


## Neurosymbols FND guide – upgrade and App

Jon was grateful to Scottish Government for Neurological Framework Funding in 2020 which supported a long needed upgrade to the neurosymbols platform in [Jul 2021](#).

Neurosymbols started in 2009 and gets around 60,000 visitors a month from around the world (50% north America).

Together with Pooja Jain and Cognihealth he overhauled the whole site and made an app. In 2022 they launched the FND formulator - an interactive tool designed to better support consultations between people with FND and healthcare professionals.



Screenshots from Neurosymbols FND guide App in Arabic, German and Finnish

The platform also welcomed alternate language translations including Arabic for the first time. We are up to 9 now, with many more in the pipeline. A lot more is planned for the future, in collaboration with people who have FND, to help make neurosymbols more useful to everyone, as a starting point (but not an end) for FND treatment.

## FND Society Update



In June 2022 we were finally able to hold the 4<sup>th</sup> international FND meeting (and first proper of the new FND Society) in Boston University. A massive amount of planning and work went in to organising this intense three day meeting, delayed from 2020 by the pandemic.

The meeting had 300 in person delegates and a further 800 online, breaking records from the previous Edinburgh meeting in 2017. It is impossible to summarise the event but like the last meeting we have no doubt that it will have helped boost an already rapidly increasing international FND research community, creating new networks and friends and bringing together patients and health professionals. Lectures are available to watch by members. If I could choose one highlight it would be [FND portal](#) telling us about his battle to get a diagnosis and the importance of FND patient advocacy. His standing ovation from the room shows how far things have come in our field.

See you for FNDS in Verona - June 8<sup>th</sup>-11<sup>th</sup> 2024! - [fndsociety.org](https://fndsociety.org)



Pictures from FNDS Boston 2022. Alan became the new President and Jon remains Secretary

# FRG HALL OF FAME 2021-2022

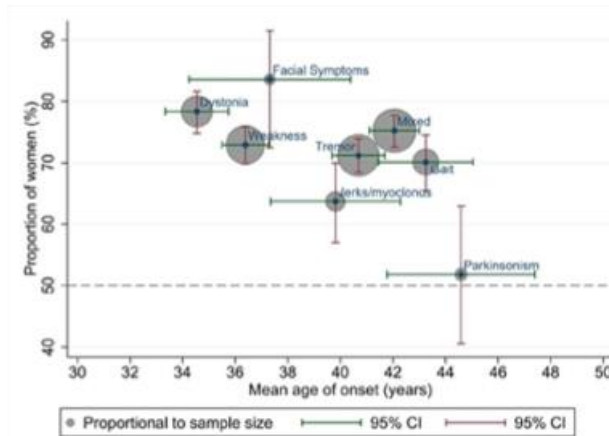
These are some of the achievements, rewards and honours the team received this year

		
<b>Alan Carson</b>	<b>Ingrid Hoeritzauer</b>	<b>Laura McWhirter</b>
Alan became the 2 <sup>nd</sup> President of the <a href="#">FND Society</a> after the 2022 meeting in Boston.	Ingrid became a valued Consultant Neurology colleague in March 2021.	Laura celebrated (belatedly) her PhD graduation in 2022
		
<b>Jon Stone</b>	<b>Sarah McRae</b>	<b>Veronica Cabreira</b>
In Nov 22 Jon was honoured to receive the ' <a href="#">John Walton Lecture</a> ' award from the Association of British Neurologists - one of their two highest honours.	Sarah joined us as FND specialist Neurophysio for the Physio4FMD trial in 2021 completing final recruitment. Sarah presented her first <a href="#">poster</a> at the FNDS meeting and we are so pleased that she has stayed part of our team.	Veronica, an accomplished neurologist from Porto, Portugal joined us in December 2021 for a three-year PhD studying Functional Cognitive Disorder as part of the <a href="#">ETUDE</a> program.
		
<b>Caoimhe McLoughlin</b>	<b>Izzy Williams</b>	<b>Sara Finkelstein</b>
Caoimhe, a consultant liaison psychiatrist from Dublin joined us in Sep 2021 as part of the <a href="#">ETUDE</a> program for a 3-year PhD studying stigma in FND.	Izzy was in Edinburgh for three years doing her DipClinPsy Clinical Psychology training. She successfully graduated having done her thesis on <a href="#">older people with functional seizures</a> .	Sara our first FRG clinical fellow 2019-2020 is now at Mass General with David Perez. But we will count her as one of ours one last time for her <a href="#">review of FND in the Emergency Department</a> among much else.



## OTHER NEWS

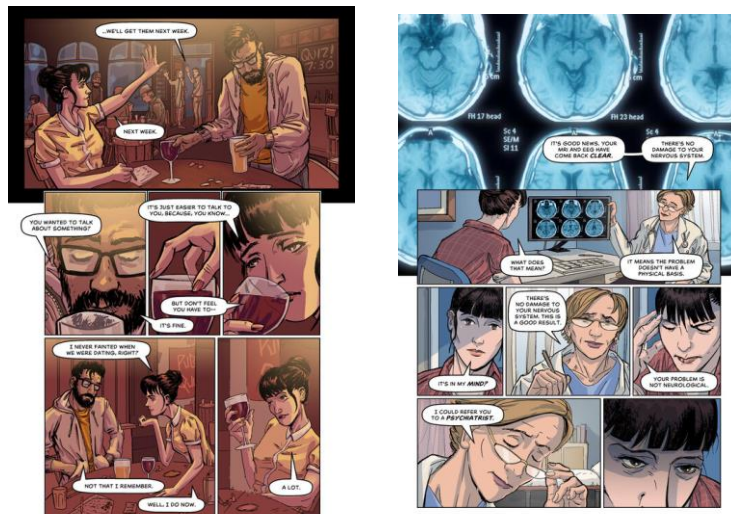
- **Working with FND Patient organisations and advocates.** FND patient led organisations including FND Hope, FND Action, FND Dimensions, FND Friends, FND Matters NI and FND Aus are central to the renaissance in interest and awareness in FND. FND advocates such as FND portal and FND recovery are also making a massive difference. Members of our group engage in a variety of activities with them such as [webinars](#), medical advisory boards and collaborating on research. Follow them on twitter to find out all the amazing things they are doing
- **Research Publications.** FRG have been involved in a large number of publications in 2021-22. Our publications are listed at the end. Much of our work is collaborative with other groups. Topics, past and future include:
  - Publications from CODES
  - Functional Cognitive Disorder
  - Scan-Negative Cauda Equina Syndrome
  - The Overlap of FND with other neurological conditions including MS and Migraine
  - A multicentre [collaboration](#) with Sarah Lidstone from Toronto looking at 4905 people with Functional movement disorder.



- Persistent Postural Perceptual Dizziness (PPPD)
- FND in pregnancy, and FND in young people and children
- FND and Chronic Urinary Retention/Fowler's syndrome
- **Media appearances.** Its great to see FND appearing more in the print and news media. Jon appeared in two BBC radio 4 programmes featuring FND, [Phantoms in the Brain](#) and [All in the Mind](#) (although FND is not 'All in the mind!'). Alan and Laura appeared on BBC [Panorama](#) and [national news](#) talking about Long Covid. Havana Syndrome and Functional Tics also led to FND being highlighted by a wide array of news outlets.

## • FND Awareness

- In October 2021 Jon helped NHS inform, the national health information site launched the first [FND page](#) on a national site like this .
- Jon and Laura co-authored a landmark review on FND in [Lancet Neurology](#)
- Jon's work in treating functional visual loss featured in David Robson's popular book '[The Expectation Effect](#)' - also serialised as a podcast.
- Jon wrote a piece for '[The conversation](#)' on functional tics and appeared on several radio shows talking about the issue as well as a webinar for Action Tourette's.
- [DSM-5 Text Revision](#) accepted the term 'Functional Neurological Symptom Disorder' in primacy to Conversion Disorder for the first time thanks to efforts from Jon and others.
- The graphic novel '[Not there](#)', written by Gavin Inglis and Fin Cramb, and advised by Jon, about a young woman's experience of functional seizures launched in Feb 2021.



- The team did many podcasts and Webinars on FND for various organisations including Science Vs, FND hope, the American Academy of Neurology, Institute of Psychiatry, Tourette Action, FND Matters Northern Ireland and others.
- Caoimhe and Veronica helped update a multilingual version of the [Functional Disorder](#) page of Wikipedia
- **Ukraine.** The [FND society](#) did its very small part to try to support Ukraine by providing free online registration for its Boston meeting to all healthcare professionals currently working in Ukraine. Jon also took part in an [FND symposium](#) for Ukrainian neurologists attended by over 300 delegates organised by Volodomir Romanchenko and Yuri Bronstein.

# OUR INSTITUTIONAL FUNDERS

As well as those individuals and groups that have generously donated to our University of Edinburgh fund we want to thank all those institutions and other organisations that have provided funding and support for us over the last few years.



- The **Chief Scientist Office for Scotland** funded our [Long Covid Research](#) as well as NRS sessions for Jon and Ingrid.
- The **Scottish Government** funded upgrade and development of the neurosymptoms digital platform through the [Scottish National Neurological Framework](#).
- The **NIHR** are funding the [Physio4FMD](#) trial led by Glenn Nielsen and funded the [CODES](#) trial led by Laura Goldstein.
- The **European Union** funded the [ETUDE](#) PhD network - 15 PhDs across Europe studying functional disorders of which Caoimhe and Veronica are two.
- The **Anne Rowling clinic**, part of the University of Edinburgh, hosts FND and Long covid research clinics.
- The **University of Edinburgh**, through the [Wellcome Trust iTPA Impact fund](#) are funding Jon in 2023 to be able to spend more time developing the Neurosymptoms FND Guide as a digital platform.
- **Baillie Gifford** funded Laura's PhD and the **Association of British Neurologists** funded Ingrid's PhD.
- The **Scottish Trauma Network** are integral to the new [brain injury service](#) at the Royal Infirmary which Alan, Ingrid and Laura are all part of.



# OUR RESEARCH PUBLICATIONS 2021-2022

## 2021

Perez D, Nicholson T, Asadi-Pooya A, Begue I, Butler M, **Carson A**, David A, Deeley Q, Diez I, Edwards MJ, Espay AJ, Gelauff JM, Hallett M, Horowitz S, Jungilligens J, Kanaan RA, Koning-Tijssen MAJ, Kozłowska K, LaFaver K, LaFrance WC, Lidstone SC, Marapin RS, Maurer CW, Modirrousta M, Reinders AATS, Sojka P, Staab JP, **Stone J**, Szaflarski JP, Aybek S. Neuroimaging in Functional Neurological Disorder: The State of the Field and Research Agenda. *Neuroimage* 2021; 30: 102623

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