



# FND Research

## 2020 REPORT

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# TO OUR SUPPORTERS

## Thank you!

A massive thank you to all the individuals and organisations that donated to the University of Edinburgh Functional Disorders Research Group in 2020.



Particular thanks to Niamh Pinkerton who did the Kiltwalk from home in 2020 raising more than £3000 for us. This was after her dad Russell had also raised a huge amount for us in a previous kiltwalk. An added bonus happened in Dec 2020, when Sir Tom Hunter

donated an additional £1000 to FRG after Niamh was selected as one his Kiltwalk Heroes. Also, many thanks to Jillian and Ron Eather who have been so consistently generous over the years in helping FRG carry out the work that we do.

Money raised by supporters of FRG has gone towards many items including: paying for website fees for the neurosymptoms.org and headinjurysymptoms.org sites, software licenses to allow data analysis, factsheets for patients and some publication costs. We are saving up for several new projects including video and animations as part of a new stigma project. We make sure that donated funds go directly to research or education for patient benefit.

We are also really grateful to our institutional funders: Baillie Gifford (who fund Laura's PhD), the ABN/Patrick Berthoud Trust (who funded Ingrid), the Anne Rowling Clinic and CCBS at the University of Edinburgh who have supported many of our research activities. The university of Groningen funded Jeannette's PhD. Thanks to the Chief Scientist Office, Scottish Government and Scottish Trauma Network who fund some of our research time and projects, online developments and related clinical services described below. Finally thanks to NHS Lothian who pay for the FND clinical service which is the basis of our research.

# OUR TEAM



The University of Edinburgh  
Edinburgh Neuroscience



## Functional Disorders Research Group in Edinburgh *Centre for Clinical Brain Sciences, University of Edinburgh*



Jon Stone  
Neurology



Alan Carson  
Neuropsychiatry



Laura McWhirter  
Neuropsychiatry



Ingrid Hoeritzauer  
Neurology



Paula Gardiner  
CBT/Physio

### FRG— Other current members



Sara  
Finkelstein  
Neurology



Clare  
Diamond  
Physio4FMD



Tommaso  
Ercoli  
Neurology



Izzy Williams  
Psychology

### Alumni and ongoing Collaborators



Hannah  
Callaghan  
CODES



Jeannette  
Gelauff  
Neurology



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



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



Lindsey  
MacGregor  
CBT/OT  
CODES



Stoyan  
Popkirov  
Trauma CRPS  
PPPD Cognition

This is the first year we have done a proper report from our research group, mainly to thank our financial supporters, explain how we are using donations and also celebrate the hard work of our team.

Our research group started around 1998 when Alan Carson first started working with Michael Sharpe and Charles Warlow on the problem of Functional Disorders in Neurology. Jon Stone joined in 1999 and the group really took off around 2010 when Jeannette Gelauff was the first of our many productive visiting students and health professionals who we enjoy staying in touch with! Ingrid Hoeritzauer, Laura McWhirter and Paula Gardiner are our other principal investigators

Now we have an amazing multidisciplinary team and a group of alumni and ongoing collaborators with whom we share research ideas and, sometimes other ideas (like what Netflix boxset to watch next, and which bottles of red are especially good value in Lidl this week!)

# 2020 HIGHLIGHTS

## Physio4FMD trial

- This year we completed recruitment to the [Physio4FMD trial](https://physio4fmd.org) - a UK wide trial of FND specific physio led by Glenn Nielsen at St Georges. See [physio4FMD.org](https://physio4fmd.org) for more. The pandemic cut things short, but Paula Gardiner did a brilliant job of following up on the outstanding patients. This will be the biggest trial of physiotherapy for FND anywhere in the world. FRG are co-investigators on the study and Edinburgh the second biggest recruiter.
- In January we welcomed Clare Diamond to the team as Research Worker. She joined us when Hannah Callaghan, our previous research worker left to do CBT training in London at the end of 2019. Clare has a degree in Neuroscience and had worked for the Stroke Association. It was a shame that almost as soon as she arrived in Edinburgh she was locked down, but we were glad to see her at the top of Ben Nevis in September enjoying Scotland in glorious sunshine.
- We also said a sad goodbye to Paula Gardiner - our “Ninja” physio4fmd and CODES therapist - more about that below.

## CODES trial

- In May 2020 the CODES trial led by Laura Goldstein was finally published in Lancet Psychiatry. This was the largest ever treatment trial in FND and again FRG were co-investigators. Edinburgh was the largest recruiter. Have a look at [www.codetrial.org](https://www.codetrial.org) for a detailed look at the results and this great animated video that explains them.



## Functional Cognitive Disorders

Laura McWhirter, whose research is funded by Baillie Gifford, had an amazing year of publications around the topic of Functional Cognitive Disorder. The research community has really responded to her thorough and common-sense approach to disentangling this neglected and important area of clinical practice.

Publications in [Lancet Psychiatry](#), [JNNP](#) and [Brain](#) (with Harriet Ball from Bristol and long cast list) throughout 2020 have all really helped put this area, and Laura, on the map.

### Functional cognitive disorders: a systematic review

Laura McWhirter, Craig Ritchie, Jon Stone, Alan Carson

REVIEW

### Performance validity test failure in clinical populations—a systematic review

Laura McWhirter, Craig W Ritchie, Jon Stone, Alan Carson

doi:10.1093/brain/awaa224

BRAIN 2020; Page 1 of 9

**BRAIN**  
A JOURNAL OF NEUROLOGY

UPDATE

### Functional cognitive disorder: dementia's blind spot

Harriet A. Ball,<sup>1</sup> Laura McWhirter,<sup>2</sup> Clive Ballard,<sup>3</sup> Rohan Bhome,<sup>4</sup> Daniel J. Blackburn,<sup>5</sup> Mark J. Edwards,<sup>6</sup> Stephen M. Fleming,<sup>7</sup> Nick C. Fox,<sup>8</sup> Robert Howard,<sup>4</sup> Jonathan Huntley,<sup>4</sup> Jeremy D. Isaacs,<sup>6,9</sup> Andrew J. Larner,<sup>10</sup> Timothy R. Nicholson,<sup>11</sup> Catherine M. Pennington,<sup>2</sup> Norman Poole,<sup>9</sup> Gary Price,<sup>12</sup> Jason P. Price,<sup>13</sup> Markus Reuber,<sup>5</sup> Craig Ritchie,<sup>2</sup> Martin N. Rossor,<sup>8</sup> Jonathan M. Schott,<sup>8</sup> Tiago Teodoro,<sup>4,14</sup> Annalena Venneri,<sup>5</sup> Jon Stone<sup>2</sup> and Alan J. Carson<sup>2</sup>

## Scan Negative Cauda Equina Syndrome

Ingrid Hoeritzauer, funded by an ABN/Patrick Berthoud Fellowship, published her PhD data on Scan Negative Cauda Equina Syndrome in [Neurology](#) in 2020. Another incredibly neglected area of clinical practice, Ingrid showed that most people being admitted to neurosurgical units with suspected cauda equina syndrome - acute back pain with bladder/bowel/leg symptoms - have normal investigations and a high proportion have evidence of FND and other functional disorders. This research, like Laura's, promises a sea change in the way clinicians approach a large number of patients who are currently told - 'nothing wrong'.

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### "Scan-negative" cauda equina syndrome: A prospective cohort study





Ingrid Hoeritzauer, Alan Carson, Patrick Statham, Jalesh N. Panicker, Voula Granitsiotis, Maria Eugenicos, David Summers, Andreas K. Demetriades, Jon Stone

First published November 11, 2020. DOI: <https://doi.org/10.1212/WNL.00000000000011154>



# FRG HALL OF FAME 2020

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

		
<b>Jeanette Gelauff</b>	<b>Ingrid Hoeritzauer</b>	<b>Laura McWhirter</b>
PhD 'cum laude' (top 5%) Groningen and <a href="#">Jan Meerwaldte Prize</a> (best Neurology PhD in Netherlands over last 2 years)	Association of British Neurologists (ABN). Charles Symonds joint 1 <sup>st</sup> award for best neurology research platform in the UK in 2020	British Neuropsychiatry Association (BNPA) 1 <sup>st</sup> and 3 <sup>rd</sup> poster prizes 2019
		
<b>Jon Stone</b>	<b>Alan Carson</b>	<b>Paula Gardiner</b>
In May 2020 Jon was honoured to receive the first ' <a href="#">Ted Burns Humanism in Neurology</a> ' award from the American Brain Foundation	Alan did an amazing job leading the education committee of the <a href="#">FND Society</a> which produced 30 hours of webinars in 2020. He was also rewarded with a deserved 3-month sabbatical in the summer	Paula celebrated her full accreditation with the <a href="#">British Association of Behavioural and Cognitive Psychotherapies</a> in Jul 2020
		
<b>Sara Finkelstein</b>	<b>Tommaso Ercoli</b>	
Sara was our first FRG clinical fellow 2019-2020 joining us from Canada for 1 year of specialist FND training. She has recently been appointed to a prestigious new job working in <a href="#">the FND unit Massachusetts General</a> with David Perez	Tommaso, a neurologist from Sardinia, joined us from Nov 19 - Mar 20. He completed his final neurology certification exams in 2020	

## OTHER NEWS

- **European Union Funding.** In January we found out that our group had been awarded two PhDs as part of an EU network of PhDs to study functional disorders. The network called 'Etude' is a Marie Skłodowska-Curie Innovative Training Network. We will be welcoming two non-UK PhDs from September 2021 to study treatment for functional cognitive disorder and stigma in FND. Email Alan or Jon if you are interested, [advert here](#).
- **The FND Society.** The FND Society ([www.fndsociety.org](http://www.fndsociety.org)) was started by Mark Hallett (NIH, USA, President), Jon (Secretary) and Alan (Treasurer) in 2019 after the successful FND 2017 meeting in Edinburgh. It was supposed to have its first meeting in Boston in June and instead we've had a successful webinar series curated by Alan, now with 30 international lectures. Membership stands at over 600 health professional members and 60 community partner subscribers. We are looking forward to an even more successful; 2021 with a face-to-face meeting planned for Boston in June 2022. Please join!
- **Research Publications.** FRG have been involved in a large number of publications in 2020. Some of our publications are listed at the end. Some of our work is collaborative with other groups. Topics include:
  - Publications from CODES and Physio4FMD trial
  - Functional Cognitive Disorder
  - Scan-Negative Cauda Equina Syndrome
  - Self-Help for Functional Motor Disorders (with Marina Tijssen and Judith Rosmalen)
  - Occupational Therapy for FND [recommendations](#) (led by Clare Nicholson)
  - Outcome measures for FND (led by Tim Nicholson and Susannah Pick)
  - FND History - including the history of FND in mid-20<sup>th</sup> century (thanks Max Fend), and the contribution of Arthur Hurst to rehabilitation models of FND (with Edgar Jones)
  - Seizures - exploring seizure ideas in the general population (led by Jakob Tiefenbach)
  - FND review in [BMJ](#) - the first since 1953!
  - *Scientific American* ran a feature [story on FND](#) in Nov 20 with our work featured prominently
- **Covid-19 work.** Alan has been involved in Coronerve - a UK wide collaboration looking at neurological and neuropsychiatric complications of Covid-19. Just before christmas we learnt that a new project studying cognition in 'long covid', led by Alan and Laura has received funding from the [Chief Scientist Office](#), Scotland



- **Neurosymptoms funding.** In September Jon was successful in obtaining funding from the Scottish Government to help upgrade the neurosymptoms website on PC, mobile and app. The project is well underway with partners Cognihealth and should be ready for an early 2020 launch. Thank you to the 450 people who helped provide feedback online for this project. New factsheets from Laura and Ingrid on Functional Cognitive Disorder and Scan-Negative Cauda Equina Syndrome are a major bonus.
- **NHS work keeps going.** During the pandemic all of the NHS Lothian medical FND clinics kept going either by phone, video or in person when we were allowed. Face to face therapies, especially physiotherapy suffered badly from the restrictions and we are aware that many people with FND have found this an especially difficult time.
- **Acute Rehabilitation for the Major Trauma Centre.** In April 2021 a new acute neurorehabilitation service will begin at the Royal Infirmary which has been supported by the Scottish Trauma Network. The Dept Clinical Neurosciences (Neurology and Neurosurgery) has moved to its new home right next to the largest emergency department in Scotland. The new acute neurorehabilitation team led by Alan aims to revolutionise the early rehabilitation of acute head injury and other acute neurological problems. The aim is to ensure that patients receive detailed assessment and rehabilitation from as early as possible after their injuries. Our team's involvement in this new service, including combine physio and psychological therapy provides new opportunities for studying and treating FND and other functional disorders in these settings.



The new Royal Hospital for Children and Young People and Dept Clinical Neurosciences at the Royal Infirmary, Edinburgh (centre of picture with helipad)

# PAULA GARDINER



Finally, we want to say a massive thank you to Paula Gardiner who has been with FRG since 2014. Paula trained as a physiotherapist and was Senior Neurophysiotherapist in Lanarkshire but in recent years trained as a Cognitive Behavioural Therapist gaining a Masters qualification over four years with Queen Margaret University. She joined us on secondment to be one of the therapists for the CODES Trial (along with Lea Ludwig and Lindsey MacGregor) and then rejoined us to be the trial therapist for the Physio4FMD trial. She combined this job with a new role as a tutor on the CBT Masters course.

Sadly, Paula is now leaving us as the arduous commute to Edinburgh from her

wonderful home near Stirling has really lost its appeal, especially after lockdown. She will now be able to spend more time with her beloved hens, and Doug! (although we know she will carry on working with the group in other ways)

Paula has been an inspirational colleague and presence in our group. Combining psychological therapy and physiotherapy gives her an incredible range of approaches for our patients with FND - which is why we know her as the “Ninja” therapist. She has contributed to consensus recommendations and worked with Glenn Nielsen on Physiotherapy research. She raised a lot of money for FRG through various events including a team Marathon.

We are also really grateful for all the work she did with some of our most complex non-trial patients with FND, many of whom had great outcomes that we doubt would have occurred without her.

Thank you Paula!

# OUR RESEARCH PUBLICATIONS IN 2020

## Original Articles

1. **Gelauff JM**, Rosmalen JGM, Gardien J, **Stone J**, Tijssen MAJ. Shared demographics and comorbidities in different functional motor disorders. *Parkinsonism and Related Disorders*. 2020; 70: 1-6
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