Massachusetts General Hospital

Founding Member, Mass General Brigham



FND Unit & Research Group Newsletter

FUNCTIONAL NEUROLOGICAL DISORDER (FND): **OUR SHARED PURPOSE**

The field of FND has come a long way. In the last 3 decades, major developments have re-shaped our understanding of this condition and have set a path for forward-thinking clinical. research, and education mission.

Nonetheless, we are keenly aware there is still much to accomplish. Specifically, we know that we need to raise awareness and continue to work across Neurology, Psychiatry, and Rehabilitation specialties advance an integrated and brain-mindpatient-centered body approach.

Thankfully, 2024 was a productive year for our team. In this FND Research newsletter, we are pleased to share with you all some of our recent programmatic research activities that are setting the stage for our future activities.

Fall/Winter 2024 ~ Volume 2

The FND Unit has grown and continues to innovate over the past year - including starting a new social work intern training program led by Ellen Godena, LICSW to number expand the psychotherapists with expertise in treating FND. Join us in welcoming Amanda Spak - social work intern. have also expanded occupational therapy care to Waltham, led by Jessica Ranford, OTR/L, and are welcoming nurse practitioner Matthew Walsh, NP to the team. In September 2023, two talented post-doctoral research fellows joined the FND Research Group: Christiana Westlin, PhD and Cristina Bleier, MD.

We are also pleased to report that FND continues to be a field of interest for people training in neurology and psychiatry, including having the privilege to work with two excellent behavioral neurology

& neuropsychiatry fellows: Laura Duque, MD and Nikita Jain, MD.

In this newsletter, we will highlight some advances in clinical care, research, education, and program development led by members of our team over the past 12-18 months.

First, we re-introduce you to our FND Unit clinical faculty, followed by a description of recently completed, ongoing, and indevelopment scientific projects from the FND Research Group. We will put a special spotlight on several promising projects led by clinician-researchers in our group that are in need of funding.

A special thank you to our patients, whom we have an opportunity to learn from and care for on a daily basis.

Topics Covered:

- 1. FND Unit (FND-U)
- 2. FND Research Group (FND-RG)
- 3. FND-U&RG Academic Highlights
- 4. Upcoming Fundraiser Event



David Perez, MD, MMSc Founder & Director FND Unit and Research Group



Sara Finkelstein, MD, MSc Associate Director, FND Unit

1. THE FND UNIT

WHO WE ARE



We are a multidisciplinary and interdisciplinary clinical team dedicated to caring for patients with FND. Our include Neurologists, Psychiatrists, Psychologists, Social Workers, Physical Therapists (PT), Occupational Therapists (OT), Speech and Language Pathologists (SLP), Nurse Practitioners (NP), Nurses, and organizational staff. Since our last newsletter, Sara Finkelstein has become the Associate Director of the FND Unit (join us in congratulating Sara!). Our team also works closely with other experts in movement disorders, epilepsy, physiatry, and neuropsychology.

We are also pleased to actively collaborate with speech and language therapists at Mass Eye & Ear and with rehabilitation experts at Wentworth Douglas Hospital. Integration across Mass General Brigham is bound to create opportunities for collaboration system-wide.





Caitlin Adams - Psychiatry



Sara Finkelstein - Neuro



Jennifer Freeburn - SLP



Ellen Godena - Social Work



Julie MacLean - OT



Julie Maggio - PT



Daniel Millstein - Psychology



David Perez - Neuro & Psych



Bruce Price - Neuro



Jessica Ranford - OT



Christopher Stephen - Neuro



Margaret Tuttle - Psychiatry



Matthew Walsh - NP



Nikita Jain: Fellow

Amanda Spak: Intern

In-Training

2. THE END RESEARCH GROUP

Newsletter

WHO WE ARE





DAVID L. PEREZ

With neurology, psychiatry, brain imaging, and neuroscience expertise, Dr. Perez founded the FND Research Group in 2014 to study the underlying biology of FND - with a keen interest in identifying clinically relevant biomarkers. As Principal Investigator, he is a big proponent of applying an integrated biopsychosocial-informed approach to FND research.



CHRISTIANA WESTLIN

Christiana Westlin, PhD, is an accomplished neuroscientist & research psychologist who is actively engaged in using a variety of structural and functional brain imaging analysis techniques to disentangle the biological mechanisms that are important in FND. You can read about her work in the research spotlight - and stay tuned for more to come soon!



From Colombia, Cristina Bleier, MD, is a smart and enthusiastic member of our team with a background in clinical psychology. She is focused on clinical research, with an interest in psychotherapy outcomes, and clinical measures for emerging areas like interoception and health anxiety. She also supports daily interactions with research participants!





ANDREW J. GUTHRIE

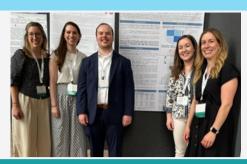
A scientifically curious and motivated person, Andrew J. Guthrie, BS, is a clinical research coordinator II in our lab. He is the one reaching out to our study participants, coordinating their visits, running the MRI scans, preprocessing data, and co-authoring articles. In other words, Andrew does a lot of great things!

IBAI DIEZ

Ibai Diez, PhD, is a highly accomplished computational neuroscientist and biomedical engineer who has applied graph-theory and other novel image processing approaches to research in FND. He is an Assistant Professor of Radiology and longstanding collaborator of the FND Research Group.



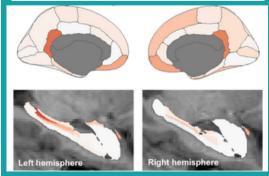
Many others are actively involved in research, including: Caitlin Adams MD, Sara Finkelstein, MD, MSc, Jennifer Freeburn, MS, CCC-SLP, Ellen Godena, EdM, MSW, LICSW, Julie MacLean, OTR/L, Julie Maggio, PT, DPT, NCS, Daniel Millstein, PhD, Jessica Ranford, MS, OTR/L, & Christopher Stephen, MBCHB.



BRAIN IMAGING RESEARCH SPOTLIGHT

In June 2024, our FND research group led by Christi Westlin and Andrew Guthrie published in the Journal of Neurology, Neurosurgery Psychiatry if subtle brain structural features can be used to distinguish people with FND both psychiatric compared to controls and healthy subjects. successfully classified participants with mixed versus healthy psychiatric controls above-chance, and classification ability became even more robust motor disorder subtype versus healthy controls. While classification efforts are ready for clinical use anytime soon, these results highlight the close connection between brain structure function. findings also encourage use of structural brain MRI future larger learning classification efforts in

Read More in our Press Release Here!



3.1 FND UNIT AND RESEARCH GROUP

Newsletter

ACADEMIC HIGHTS

This year has been a success and we want to share a few achievements with you. Our productivity stems from a shared passion for bettering the lives of people with FND, as well as a deep interest in investigating diagnostic, biological, and treatment questions in this population.

Neurology Clinical Practice

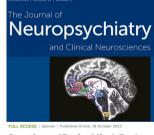
RESEARCH ARTICLE | April 9, 2024

Sensory Processing Difficulties and Occupational Therapy Outcomes for Functional Neurological Disorder

A Retrospective Cohort Study

Kathryn E. McCombs, OTD, OTR/L . Julie MacLean, OTR/L . Sara A. Finkelstein, MD, MSc , Susan Goedeken, MS, OTR/L . David L. Perez, MD, MMSc . , and Jessica Ranford, MS Jessica Ranford and Julie MacLean, two neuro-occupational therapists, are trailblazing in using occupational therapy to treat sensory processing difficulties in patients with FND. They were the first to discover and replicate findings of self-reported sensory processing difficulties in 121 individuals with FND. They have also developed and published an 8-module Sensory Modulation Treatment that aims to identify and address links between the sensory system, the central nervous system, and emotion/bodily regulation -- to help patients manage FND symptoms and engage in meaningful activities. In a *Neurology: Clinical Practice* retrospective study, 62% of 77 people receiving this OT Sensory Modulation Treatment reported some improvement in their FND symptoms and/or return to life roles and routines. We are now actively exploring funding opportunities to allow our FND Research Group to conduct a clinical trial in this promising occupational therapy treatment!

Julie Maggio and Caitlin Adams authored an opinion paper in the Journal of Neuropsychiatry & Clinical Neurosciences that considers how several diagnoses, including FND, persistent symptoms after concussion, chronic pain disorders, fibromyalgia, disorders of brain-gut interactions, and somatic symptom disorder can be conceptualized as Brain - Mind - Body Interface Disorders. These conditions share biological similarities and treatment principles, emphasizing the importance of having multidisciplinary care and a collaborative stance between patients and their treatment team. Despite this, biopsychosocial considerations remain an important underdeveloped area of research inquiry, a topic that Caitlin Adams aims to address by launching a new research project investigating biopsychosocial complexity and healthcare utilization in patients with FND compared to those with epilepsy. Support this project with a donation!



Creating a "Brain-Mind-Body Interface Disorders" Diagnostic Category Across Specialties



FND Unit members were active in the planning and delivery of educational content for the Functional Neurological Disorder Society's (https://www.fndsociety.org/) 5th International Conference. Noteworthy contributions came from Sara Finkelstein who spoke to the general assembly on "Common Skills for Assessing a Patient with FND", and Julie Maggio (a lead planner for the educational day) who spoke on "Common Language for Diagnostic Delivery, Educational Models to Understand Symptoms". Julie also chaired the rehabilitation education track, where our lead speech and language pathologist Jennifer Freeburn was a featured speaker. Ellen Godena and David Perez also presented - providing case-based commentaries. Pictured on the left are Julie, Sara and Jennifer (left to right) enjoying the opera in Verona, Italy - the site of the FND Conference held in June 2024.

4. FND UNIT AND RESEARCH GROUP

Newsletter EVEN MORE HIGHLIGHTS& FUND RAISER!



In a paper published in *NeuroRehabilitation* led by speech and language pathologist Jennifer Freeburn and summer student Lex Goldstein, we reported on 20 patients with functional speech disorder that underwent treatment. At assessment, most had other functional motor symptoms and had overlap between the 3 main types of functional speech presentations - highlighting the common occurrence of mixed symptoms. Here, 18 of 20 patients improved at least somewhat - 8 of which received some portion of treatment via video telehealth. We now aim to run a pilot clinical trial for telemedicine delivery of speech and language treatment for functional speech disorder. Support this project with a donation!

Why are we fundraising? Raising Awareness & Impact

As many of you know, FND is a common reason to see a neurologist across inpatient, outpatient, and emergency department settings. However, research funding has lagged behind the support provided to other complex brain disorders.

That is why we need your help!

JOIN US FOR A PATIENT-LED FUNDRAISING & COMEDY NIGHT EVENT

Organized and led by Kyla Madonna Kenney [Thank You!]



<u>Date/Time</u>: November 16th, 2024 7pm - 10 pm ET; \$25 Entry <u>Location</u>: 381 School St, North Kingstown, Rhode Island

<u>Event Includes</u>: Funny 4 Funds Comedy Show, Silent & Live Auction, 50/50 Raffle ALL PROCEEDS GO TO SUPPORT THE MGH FND UNIT & RESEARCH GROUP

Register & Join Us for this Fundraiser!

Can't make it? Donations still appreciated!

Donate & Support our Clinical, Research & Education Innovation Efforts

If interested and able, you can support our work by making a gift/donation to the FND Unit & Research Group. Your gift will go directly to clinical and research development in FND.

Click here to send a donation/gift.