

'Can't do it without you'

Sounds like a music lyric but it's true.
Our research is only possible when there are
people with MS to contribute the data.

Since May 2006 the MS clinic at the John Hunter Hospital has participated in over 30 studies; covering basic science to clinical care to pharmaceutical trials.

This newsletter aims to give you feedback on the studies you've participated in. It will also describe some of the studies that are in the pipeline or currently recruiting, in case you're interested to be part of them. If you are interested contact the study coordinator associated with that study (on the last page).



RESEARCH UPDATES

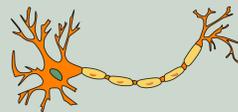
Study name: BAC-MS

Study purpose: To assess the cost of MS to the Australian health care system, patients and their families as well as society in general. It was the first study to compare the NDIS package values to internationally accepted disability standards.

Study outcomes:

1. That NDIS plans vary widely between people.
2. Higher EDSS (disability score) usually meant more NDIS support was provided.
3. Cognition levels (brain function) contribute to the cost of living with MS.

Study Importance: This study was significant because it highlights the importance of all aspects of MS, physical, cognitive and psychological burden. The last two of which are often overlooked.



Study name: Mindfulness and Pilates for fatigue study

Study purpose: Between COVID lockdowns last year, we did a study that compared mindfulness based stress reduction techniques (similar to meditation) to a Pilates class.

Study outcomes: We found that both mindfulness and Pilates reduced the IMPACT that fatigue had on lives, but didn't quite reduce actual fatigue levels enough to call the results significant. However, this study was small so we now need to do this again with a larger group of participants. So watch this space!



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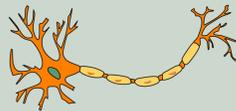
Study name: Diffusion Tensor Imaging in MS

Study purpose: We compared nerve fibre connections of people with MS(pwMS) on Fingolimod, Tecfidera or Injectable therapies with healthy controls (HC). We correlated the disruption of measured connections with brain atrophy measures and clinical outcomes.

Study outcomes:

1. Compared to people without MS, pwMS have disrupted connectivity.
2. This correlated moderately with disability status.
3. These parameters also showed a moderate correlation with cognitive function.

Study Importance: Demonstrating how lesions disrupt connectivity in MS might be better correlated to clinical outcome than just counting new lesions.



Study name: Neurometabolic changes in MS

Study purpose: We compared neurometabolic parameters in the MRI of pwMS on fingolimod or injectable therapies with scans from healthy controls (HCs).

Study outcomes:

1. There were significant changes between the metabolic profile of pwMS and HC.
2. There was no difference between treatment groups.
3. Especially in certain regions of the brain (hippocampus, posterior cingulate gyrus (PCG) and pre-frontal cortex (PFC)) we found moderate correlation of glutamate and GABA with cognition and fatigue functions.

Study Importance: This study demonstrates that independent of treatment type if clinically stable, the neurometabolites can be improved



Study name: ARTiMS (Artificial Reproductive Technologies in MS)

Study purpose: To better understand the experience of subfertility in MS and the key gaps in care.

Who is eligible?: Women with MS or Neuromyelitis optica Spectrum disorder (NMOSD) who have experienced or are currently experiencing subfertility

Recruitment Start: early to late 2023

Study contact: Susan Agland



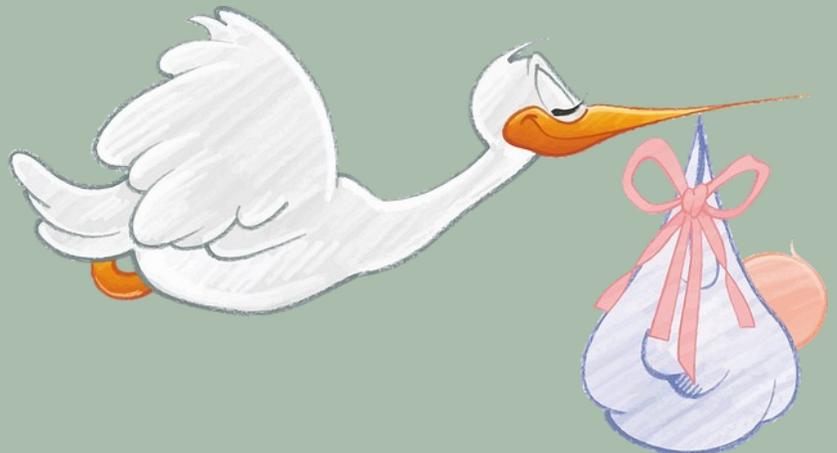
Study name: Immunobiology in MS and NMSOD

Study purpose: To better understand the experience of pregnancy in MS

Who is eligible? Women with MS or NMSOD who plan to become pregnant

Recruitment Start: early to late 2023

Study contact: Vicki Maltby



Pipeline and recruiting
Research



Study name: RELIEF (Researching the Effectiveness of a nutraceutical Intervention for multiple sclerosis related Fatigue)

Study purpose: to determine whether dietary supplements (like vitamins and antioxidants) can help relieve fatigue in MS

Who is eligible? People with RRMS who are experiencing fatigue

Recruitment: Until end 2022

Study contact: Kira Groen



Study name: Floodlight MS – More Active

Study purpose: to test whether a smartphone app can characterise and predict disability in MS which may help your neurologist better manage your MS in the future

Who is eligible? People with MS who own a smartphone

Recruitment Start: Soon! (expected late 2022)

Study contact: Nicole Lingard/Kira Groen



Pipeline and recruiting

Research

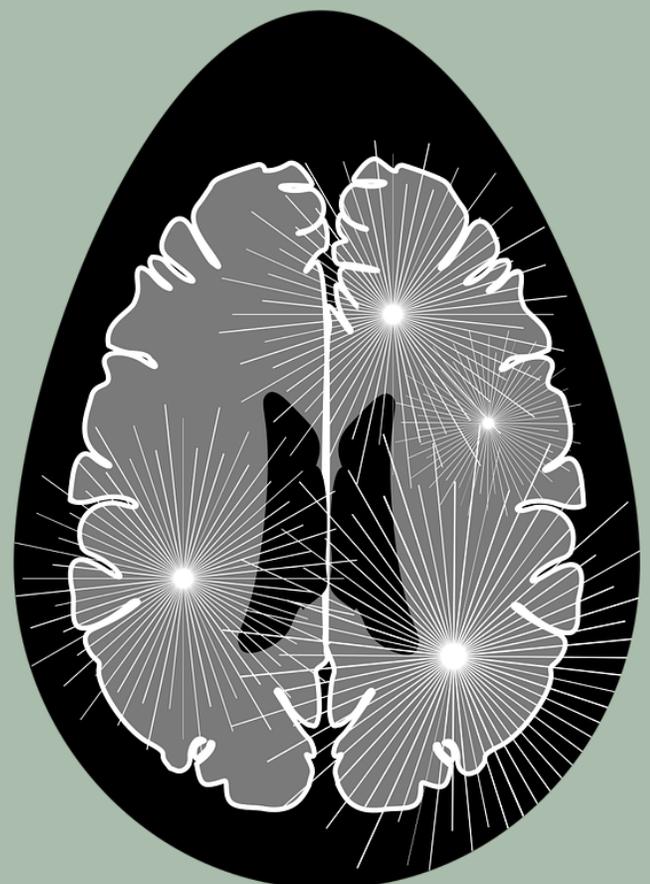
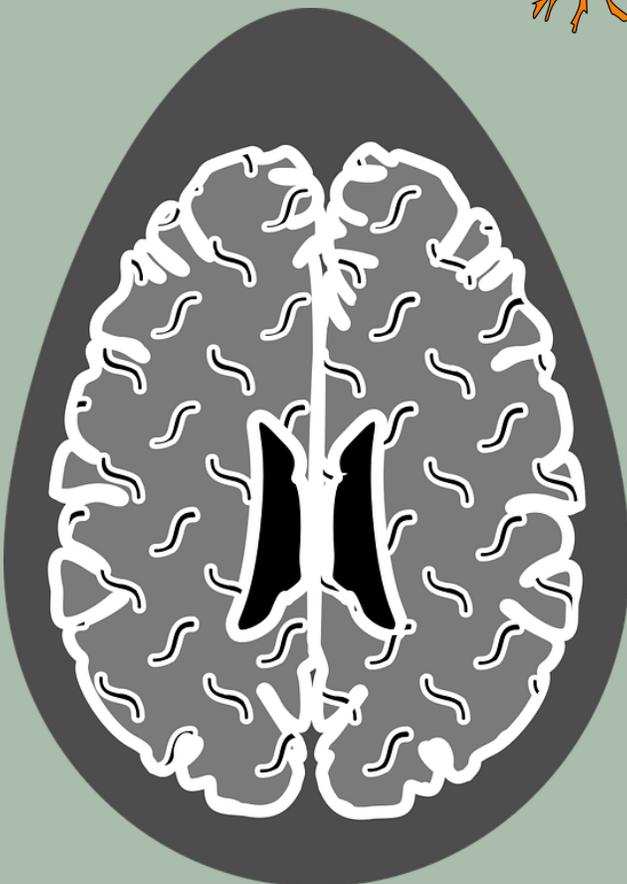
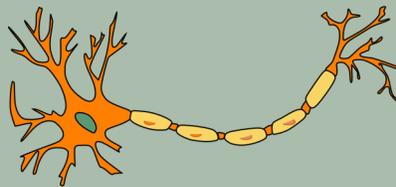


Study name: TAURUS (magneTic brAin stimUlation foR mUltiple Sclerosis)

Study purpose: To determine if magnetic brain stimulation can help repair myelin in MS.

Recruitment Start: starting Sept/Oct 2022

Study contact: Nicole Lingard





General study information

Australian Clinical Trials: [How clinical trials work](#)



Recruiting Study Contacts

ARTiMS: susan.agland@health.nsw.gov.au, 49213540

Pregnancy in MS: vicki.maltby@health.nsw.gov.au, 40420286

RELIEF: Kira.Groen@health.nsw.gov.au, 40420304

Floodlight: Nicole.lingard@health.nsw.gov.au or kira.groen@health.nsw.gov.au

TAURUS: Nicole.lingard@health.nsw.gov.au 02 40420310



Links to Published Articles

BAC-MS: <https://www.publish.csiro.au/ah/AH21056>

[https://www.msard-journal.com/article/S2211-0348\(22\)00222-X/fulltext](https://www.msard-journal.com/article/S2211-0348(22)00222-X/fulltext)

MRI: https://journals.sagepub.com/doi/10.1177/19714009211067400?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%20pubmed