



# '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 some of 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). Did you know???

We now have a clinic website that has updates, useful links for you and links to our research and presentations and podcasts.

Why not check it out? <u>https://bit.ly/MSNewcastle</u>

# World MS Day is May 30th and we are hosting a public seminar!

We have a series of great local and invited speakers to talk about everything from diet to brain health. You will also have a chance to meet our consumer group, enjoy some light refreshments and have your questions answered in a Q&A session



Date: May 30th Time: Day seminar 2:30-4:30 pm. Evening Seminar 6-8pm Location: John Hunter Hospital theatre RSVP: hnelhd-msclinic@health.nsw.gov.au

Please check out our website for more details.



# **RESEARCH RESULTS**

# **Dairy and Gluten in MS**

**Study purpose:** The purpose of this study was to look at whether consuming dairy and gluten has any benefit to MS outcomes. This was based on a survey sent out in clinic which 270 of you responded to. Thank you!

**Study outcomes:** We found that people who consumed dairy and gluten did not have different disease outcomes to those who cut dairy and gluten from their diet. We also found that excluding dairy and gluten did not make any difference to their quality of life.

**Study Importance:** There are many diets suggested for people with MS. However, the recommendations for each of the different diets are different and often difficult to follow because they require exclusion of specific food groups. The main message from this study is that a healthy well-balanced diet, that means the Australian healthy eating guidelines found here: <u>https://www.eatforhealth.gov.au/guidelines/australian-guide-healthy-eating</u>, is probably the best strategy.

#### Click here to read our article.



# Cell-specific epigenetic age acceleration in people with MS

**Study purpose:** The purpose of this study was to look at whether the cells that make up the immune system in people with MS appear older than the cells of the immune system in people without MS.

**Study outcomes:** We found that people with MS do have an older immune system than people without MS, but that this is specific to only one type of immune cell. These are called B cells and they are the cells of the immune system that produce antibodies when we have an infection. It was particularly aged in people who smoke.

**Study Importance:** This is important because as the cells in our immune system age, it doesn't work as well as it used to. This can lead to slower recovery times, other diseases and slower ability to detect disease. What can you do to slow this aging down? Quit smoking if you smoke, eat a healthy balanced diet, and get regular exercise.

Click here to read our article.



**RESEARCH RESULTS** 

# You are more than your DNA

**Study purpose:** There is a known genetic link with MS, however, not everyone who has MS, has this genetic link. The purpose of this study was to look at other factors that might cause MS. These are known as epigenetics. Epigenetics can be inherited like genes, but also influenced by lifetime events like smoking. They are also reversible. We think it may be the missing link to why some patients develop MS despite not having the genetic link.

**Study outcome:** We found that there are epigenetic changes in people with MS that are completely separate from genetics. We found that these epigenetic changes are mostly in B cells (the antibody producing immune cells) and monocytes (one of the immune cells that destroys "invaders" like viruses.)

**Study importance**: This study helps us understand the importance of how genetics and environment: may contribute to MS development.

Click here to read our article.



#### Response to Interferon Beta can be predicted with epigenetics

**Study purpose:** Interferon Beta was one of the first therapies for MS. However, even now it is not really understood why interferon beta works for MS. This study was looking to see if there is anyway we can tell when someone's MS is stable while taking interferon beta and when they might need to change treatment.

**Study outcome:** We looked at the epigenetic changes (see above for explanation of epigenetics) in the immune system before and after interferon beta treatment. We were able to create a "risk score" that shows when someone becomes stable on treatment. We also learned that beta interferon interacts with anti-viral machinery.

**Study importance**: This study might help us provide a way to predict if a treatment is going to work before someone starts taking it. Or at least monitor if a treatment has stopped working. Not many people use interferon beta anymore, but we can apply this knowledge to other treatments now.

Click here to read our article.



# PREVANZ—the vitamin D study

**Study purpose:** To see if vitamin D supplements can delay the time to a confirmed MS diagnosis and reduce disease activity.

**Study outcomes:** There were 200 people who participated in the trial throughout Australia and New Zealand. Vitamin D supplementation was well tolerated but there was no change in time to confirmed diagnosis or disease activity between the groups.

**Study importance:** This study shows that while vitamin D is safe to take, it cannot replace regular MS treatments.

Click here to read the article.



# A longitudinal analysis of brain volume changes in MOGAD

**Study purpose:** To investigate brain volume changes in people with MOG antibody associated disease (MOGAD) over time.

**Study outcomes:** Over a 2-year period, most brain matter lost in MOGAD occurred in the grey matter. Grey matter makes up the outer most layer of the brain and contains less myelin (the fatty sheet that wraps around nerves) than the white matter.

**Study importance:** Ongoing brain matter loss in MOGAD suggests that regular MRIs might be useful for people with MOGAD to keep an eye on their disease, similar to MS.

Click here to read the article.



# Diffusion MRI can help monitor fatigue and disability in MS

**Study purpose:** To investigate the relationship between microscopic structures in the brain (white matter tracts) and fatigue and disability in people with MS.

**Study outcomes:** Microscopic structural changes in white matter tracts of the brain (the parts of the brain that are covered in myelin) were correlated with both fatigue and disability in people with MS.

**Study importance:** Identifies connections between specific white matter tract integrity, fatigue, and disability in MS.

Click here to read the article.

**RESEARCH RESULTS** 

# MR myelin imaging in multiple sclerosis

**Study purpose:** To assess the potential of advanced MRI techniques for evaluating myelin repair therapies in MS.

**Study outcomes:** Multiple myelin imaging measures correlated with disability, disease severity, and duration.

**Study importance:** These techniques may allow us to determine the efficacy of new research and therapies that are designed to repair myelin damage in people with MS.

Click here to read the article.



# Metabolic MRI in people with multiple sclerosis.

Study purpose: To evaluate amide proton transfer-weighted signal (a MRI technique that looks at chemical changes in the brain) in multiple sclerosis lesions.

**Study outcomes:** Amide proton transfer-weighted signal was able to differentiate between MS lesions and normal-looking brain with an accuracy of >75%.

**Study importance:** Amide proton transfer-weighted imaging has the potential to provide essential chemical information about MS lesions and disease processes using MRI scans.

Click here to read the article.



#### Understanding Changes in cognitive function in Multiple Sclerosis using MRI

**Study Purpose:** To identify brain imaging markers that can predict changes in cognitive function over a 5-year period in people with multiple sclerosis.

**Study Outcomes:** A combination of different MRI techniques could help predict changes in cognitive function in MS.

**Study Importance:** This research is crucial for improving the early detection and management of cognitive decline in MS patients. By identifying specific brain markers associated with cognitive changes, clinicians can intervene earlier and potentially develop targeted therapies to improve the quality of life for individuals with MS.

#### Click here to read the article



#### 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: open

Study contact: Susan Agland or Vicki Maltby

Or hop onto the internet and take the survey: https://redcap.hmri.org.au/surveys/?s=LFAKWW8K3DKT8KW4



#### 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 and have never been pregnant before.

We are also looking for women *without* MS who have just become pregnant for the first time. If you have a friend who just announced they are pregnant and they want to help, please pass on our details!

Recruitment Start: open

Study contact: Vicki Maltby







#### 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: Open until July 2024

Study contact: Tom Woodcock or Nicole Lingard



#### Study name: FIRMS-EBV, Platypus and STOPP-MS

**Study purpose:** In the near future we have a number of trials starting that are designed to look at the impact of anti-viral therapies to determine the impact of EBV on people with MS. One will investigate if anti-virals can stop the fatigue associated with MS, the others will look at relapse rate in either relapsing MS or progressive MS.

Who is eligible? Please speak to your neurologist about eligibility

Recruitment Start: mid-late 2024





# 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

Floodlight: Thomas.woodcock@health.nsw.gov.au



For other information about trials and contact information, please see our website.

https://bit.ly/MSNewcastle