

THE OFFICIAL NEWSLETTER OF MULTIPLE SCLEROSIS RESEARCH AUSTRALIA



Deciphering Gut Health

Diet and gut health are important in MS, but it is an area fraught with seemingly complex and contradictory advice.

The internet is full of information on probiotics, prebiotics and antibiotics and we are constantly bombarded with messages to fast, selectively feast and detox, with literally hundreds of diets all with their celebrity advocates. But sometimes the hype runs faster than the evidence.

Diets and attempts to improve gut health are nothing new, and we are gathering more evidence for such interventions. But people are right to be sceptical because history is littered with examples of “proven” diets which now just seem a little ludicrous. This includes

the Mastication Diet – a fad in the late 1800s which argued that unchewed food was the root of a number of health problems.

However, recent improvements in DNA sequencing technology and the ability to simultaneously test hundreds of samples have transformed scientists’ ability to perform research on gut bacteria and their effects on health and disease. MS is just one area where scientists are exploring this, and it is resulting in a tremendous increase in knowledge of how bacteria affect our health.

What is the role of gut bacteria?

The gut contains tens of trillions of microorganisms, and at least 1,000 different bacterial species. Research into animals that are devoid of bacteria have shown that gut bacteria play a role in our stress response, alter our immune systems, and potentially induce changes to our blood-brain barrier. The challenge now is to decipher how bacteria are doing this, which bacteria are important, and for the MS community the question becomes — what role does gut bacteria play in MS?

(continued page 2...)



A WORD FROM OUR CHIEF EXECUTIVE OFFICER

As part of the marking of our 15th year, we have been talking with many people affected by MS about what the current rate of progress over the last decade and a half means to them; as well as the obvious treatment and breakthrough gaps and the success that is clearly yet to be achieved.

MS scientists, health economists and epidemiologists (researchers on a population scale) provide the proof of where quality of life and health savings have been enhanced in terms of newer and more treatments, bettered employment outcomes, speedier diagnosis, reduced hospitalisations, upgraded symptom management options, refined knowledge on the causes of MS, and so on.

Communicating this proof via our socials, newsletters, conferences, media and in person to our audience is part of our DNA.

The obvious challenges are:

1. MS affects a wide age range of people who may consume their information very differently
2. The disease is sometimes markedly different from one person to another
3. There is more than one form of MS and the treatments available and progress seen is quite different.

Despite these communication challenges, it is imperative that we continue to provide all people with MS, their friends, families, researchers, donors, government and the general public, evidence-based information

which is rarely stagnant and is constantly evolving.

Seven years ago, we were not able to convey these messages to our younger audience quite as well as with others who may have been further along the MS journey. *Kiss Goodbye to MS* was borne and over \$7.5 million raised, nearly 100,000 likes on Facebook received, over 15 countries participated and numerous awards won — there is great evidence that our communications to a younger audience has hit the mark. Similarly, there was a great need to convey not only hope but progress for people living with progressive MS. Many years ago, we joined the International Progressive MS Alliance as a managing member with 5 other countries and we now have a global movement dedicated to finding solutions for the approximate 1 million+ people worldwide living with progressive MS. Someone once told me that they were not sure that we would ever see a registered treatment for progressive MS. Hopefully, by this time next year we will have three. But this will only help some. Now, we turn the bedrock of our attention to ensuring that all people with progressive MS have effective treatment options.

We exist simply because there are people living with MS in Australia and research is the conduit for a cure within our lifetime. We take our ability to convey this message seriously and we are thrilled to be nominated for the 2019 'PRIME Awards – NGO of the Year'; specifically, in the field of healthcare communications. We may have come a long way but we are focussed on improving even further over the next 15 years.

Conveying progress and breakthrough is always easier once you realise exactly where you have come from. To that end, we are asking our subscribers to provide your opinion on the top breakthroughs or improvements within MS over the last 15 years, so that we can expand and explain these further to our entire audience.

Please send your thoughts to enquiries@msra.org.au

Dr Matthew Miles, CEO



Deciphering Gut

Gut bacteria and MS

The problem with looking at associations between gut bacteria and MS is what comes first – did the changes in gut bacteria help contribute to the development of MS, or did the gut bacteria change because of MS?

There have been a number of studies published in prestigious scientific journals trying to answer this question. These studies include research which took bacteria from people with MS and without MS and transplanted them into a laboratory model of MS. Findings have shown that gut bacteria from people with MS can lead to an increase in MS and also an increase in MS severity, showing that gut bacteria are important in not only the development of MS, but potentially in the severity of the disease as well.

It is important to note in these studies that bacteria from people without MS did not totally prevent MS, and that these laboratory studies may not totally reflect what is happening in the real world. However, they do suggest that gut bacteria are important but are not the only factor contributing to the development of MS.

The next step is to try and understand how bacteria in the gut might affect the brain and immune system. One way is through their interaction with neurotransmitters (chemicals that act as a means of communication between brain cells). One example is serotonin,



Health continued...

commonly known as the happy chemical. While we predominantly think of serotonin as a brain chemical, the majority of the body's serotonin is located in the gastrointestinal tract and our gut bacteria can regulate how much serotonin the body produces. This in turn influences both mood and gut activity.

Another way our gut bacteria could be influencing the body is by breaking down food into different components, some which are probably beneficial and others that might be detrimental. This is where the word prebiotic comes in — prebiotics are foods or chemicals that induce the growth or activity of beneficial microorganisms. Our gut bacteria break down these chemicals into individual components. For example, some bacteria break down prebiotics into short-chain fatty acids. These short-chain fatty acids have been shown to be protective to brain cells, and in laboratory models of MS when fed a diet high in short-chain fatty acids or high dietary fibre, the severity of MS appears to diminish. This further suggests a role for gut bacteria and diet in MS.

But it isn't just the gut's interaction with the brain that is important. Our gut bacteria can influence our immune system. There has been a range of studies on this, and of particular interest are the studies looking at transplanted gut bacteria from people with and without MS. In laboratory models that

received gut bacteria from people with MS, lower levels of an immune system chemical called IL-10 were observed. IL-10 is a chemical known to play a 'calming' regulatory role in the immune system. These laboratory studies suggest that bacteria from people

“These short-chain fatty acids have been shown to be protective to brain cells, and in laboratory models of MS when fed a diet high in short-chain fatty acids or high dietary fibre, the severity of MS appears to diminish.”

with MS might be causing the body to produce less of this calming chemical, resulting in a more active immune system.

How can we ensure good gut health?

So if the gut is linked to brain health and it is vital, isn't the case closed? Well, the challenge remains to determine which bacteria are playing a role, and how do we encourage them and not the

bacteria that are detrimental — this is not an easy task. To put it into perspective, if we think of all the different animal species that live in the world, and how different they are, bacteria are exponentially more diverse and abundant. Additionally it is estimated that over 80% of the bacteria in our stomachs can't be grown in the laboratory, so it is literally a case of finding needles in this gigantic haystack of life.

The good news is that studies have shown that changes in diet can lead to rapid changes in gut bacteria. Although there is still a long way to go, a number of foods are thought to generally help our gut bacteria, including fermented food (e.g. yoghurt), foods high in fibre, and eating foods of different colours (as some of the chemicals that make them colourful can be beneficial). For more information, you can watch a webinar recently presented by MS Research Australia funded researcher and accredited dietitian, Dr Wolfgang Marx youtu.be/t9DGDuBoT9M.

We strongly recommend that if you are thinking of changing your diet, you talk to your healthcare team and consult with an accredited dietitian.

Want to know more?

MS Research Australia has been reporting the latest research findings about gut health and MS for many years.

Please visit us at msra.org.au and search for "gut health".



New biomarkers may predict MS progression

The damage to myelin seen in MS is caused by inflammation resulting from an immune system attack on the brain.

The level of inflammation early in the disease, captured through measuring lesions can, to an extent, predict longer term clinical outcomes. However, this is not the full story as lesions don't completely account for MS progression, and the second stage of MS where nerve cells are lost and disability starts to accumulate without any inflammation. This means there is an urgent need for biomarkers – things that can be measured to indicate a biological process – that can be detected earlier in the disease and more accurately predict MS progression.

A team of Australian researchers led by Ms Sanuji Gajamange, a postgraduate scholar funded by MS Research Australia, and Dr Scott Kolbe, were interested to see whether changes linked to the loss of nerve cells, measured using magnetic resonance imaging (MRI) and optical coherence tomography (measures the retinal thickness in the eye), would be able to predict longer term MS severity.

What did the researchers do?

The researchers followed 36 people with Clinically Isolated Syndrome (CIS). CIS refers to a first attack of neurological symptoms and it can be a precursor for MS for some people. A second attack is required in order to be diagnosed with MS. The researchers looked at differences in lesion measurements and the loss of nerve cells between those who eventually developed MS and those who didn't.

Specifically the researchers were interested in the loss of brain tissue volume, changes in the brain structure, and the thickness of the layer of nerve cells at the back of the eye. The team looked at whether these measurements early in the disease could be used as predictors of longer term MS severity in people at the very earliest stages of disease (those with CIS).

For those people who did go on to have a diagnosis of MS, the researchers also looked at which of these measurements over the first 12 months could predict the time to a second relapse (and therefore a diagnosis of MS), the number of relapses overall and disability accumulation over many years, up to 10 years in some participants.

Lesions were different in people who went on to have MS

The researchers found that 69% of people with CIS went on to have MS. They found that there were a number of differences between the characteristics of lesions in the first 12 months in those who went to have MS and those who didn't.

- Almost a third of the people who converted to MS had active lesions when they first presented, while the people who didn't convert to MS didn't have active lesions.
- People who ended up with MS had a larger number and larger volume of lesions when they first presented compared to those who didn't convert to MS – these were linked to a second relapse.

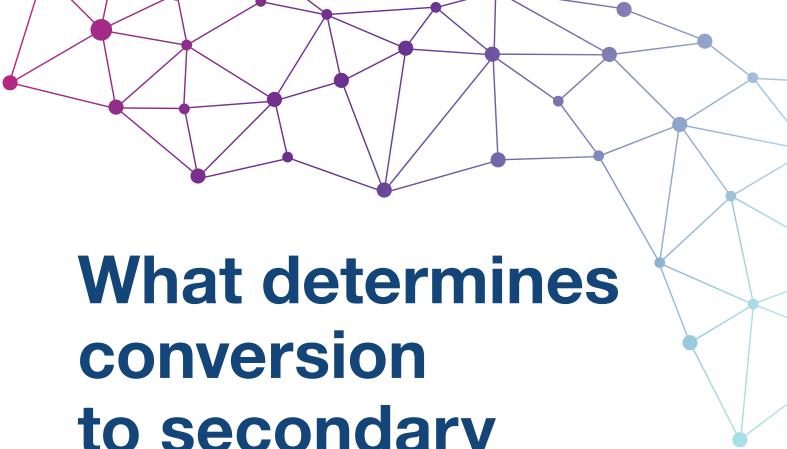
Interestingly, disease-modifying treatment had no impact on the time to second relapse. These findings suggest that inflammatory activity is the main driver of relapses.

What about the measurements related to nerve cell loss?

The researchers found that people who converted to MS had greater brain volume loss and more thinning of the layer of nerve cells at the back of the eye compared to people who did not go on to have MS. They also found that if this nerve layer thinning started earlier, it predicted the final level of disability seen in those people.

What do these results mean?

These exciting findings suggest that early measurements relating to the loss of nerve cells could improve the prediction of longer term severity of MS, including disability progression. While further studies will be required, knowing whether someone is more likely to convert to MS or have worse outcomes could inform treatment decisions earlier in the disease and hopefully, prevent them.



What determines conversion to secondary progressive MS?

Secondary progressive MS (SPMS) is a form of MS that usually follows on from the most common form of MS, relapsing remitting MS (RRMS).

Conversion to SPMS means that rather than symptoms of MS coming and going, disability slowly starts to accumulate over time. At the moment, it is hard to determine who is most likely to convert to SPMS and when this might happen to someone.

Why are risk factors for SPMS important?

There have been studies looking at factors linked with the development of SPMS, but most of these have been limited to certain geographical locations, have only examined factors in the first few years after MS onset, or consist of people who haven't received treatment. If left untreated, up to 80% of people who have RRMS are at risk of developing SPMS, but we know that with treatment this number is much lower. However once a person converts to SPMS current treatments are less effective. There is an urgent need to identify risk factors that can predict progression of RRMS to SPMS while taking into account the current landscape of treatments available for MS, and this is what researchers are trying to establish.

What is the latest in this area of research?

A large international study, led by Australian researcher Associate Professor Tomas Kalincik from the University of Melbourne, used data from an international clinical database called MSBase, to look at factors that influence the development of SPMS. This database captures information about treatments and outcomes from thousands of people with MS worldwide. Published in *Multiple Sclerosis Journal*, the study involved multiple analyses of the demographics, clinical data, as well as magnetic resonance imaging (MRI) data and cerebral spinal fluid (CSF – the fluid surrounding the brain and spinal cord) in people with RRMS.

The first analysis focused on demographic factors such as age and sex, and clinical data such as disease duration, number of relapses per year, number of relapses in the previous year, disease-modifying treatment (DMT) length and disability progression in over 15,000 people, and their link to conversion to SPMS. The second analyses involved clinical data as well as MRI brain data (6,145 people), MRI spinal cord data (1,745 people) or CSF (3,105 people), and their link to conversion to SPMS.



What do the results show?

Of the 15,717 people included in the first analysis, 85% received DMT and 10% converted to SPMS. The average time to convert was 32.4 years. Greater disability, rapid disability progression, higher number of relapses in the previous year, longer disease duration and older age were each linked to increased risk of SPMS. DMT and an improvement in disability based on the expanded disability status scale (EDSS), were linked to a reduced risk of SPMS.

Adding the data from brain MRIs mostly confirmed these results. However, in this smaller second analysis group, DMT usage, the number of relapses in the previous year and MRI evidence of disease activity were not linked to SPMS risk. For those people where spinal cord MRI data was available, spinal cord lesions were not linked to SPMS risk. For those people with CSF data, a link was not found between the presence of oligoclonal bands (the bands of antibodies) in CSF and the development of MS.

What does this all mean?

These important findings show that the risk of conversion from RRMS to SPMS increases with older age, longer disease duration, greater disability, rapid disability progression and a higher number of relapses in the previous year, and decreases with better recovery from disability. They also show that DMTs may reduce the risk of conversion to SPMS, which is supported by other studies. The average time from MS onset to SPMS has increased from 15 years to 30 years over the last two decades, and this study has confirmed this, highlighting the efficiency of treatment options available to people with MS.

These findings will be important for clinicians to help them identify people who are at high risk of developing SPMS at an earlier stage. This means that interventions can be started earlier, reducing people's chances of ever developing SPMS.

A pirouette to Kiss Goodbye to MS



One of our Kiss Goodbye to MS fundraisers explains what motivated her to host an event to raise money for vital MS research.

Hi, my name is Cathy Atkin, I am 58 years old and have been living with MS for approximately 15 years. This year, I decided to support Kiss Goodbye to MS by hosting my very own fundraiser to raise much needed funds for MS research.

Due to the amazing researchers here in Australia and globally developing new medications, I am able to live a relatively normal life. Exercise is a very important part of my life, and I am so grateful to have found a local ballet studio that has not only made ballet an all-time favourite hobby of mine, but has helped me to become stress-free and more balanced.

Over a cup of coffee, my ballet teacher and I came up with a great idea to host a fun ballet dance class and afternoon tea. It was not only to raise funds for Kiss Goodbye to MS but also to raise awareness of this 'silent disease'. What better way to host an exciting fundraiser than to get a group of ladies within the community to come together for a great cause and try something new!

I spoke to my family and friends about my fundraiser and they were nothing but proud and thrilled to support me. A lady at my local aged-care facility that I volunteer at, has MS, and the feedback that I received was incredible.

It's the best feeling to know that I am on the right track and that what I'm doing is having such a positive impact on the people around me.

Throughout the whole experience of organising this fundraiser, it's been very rewarding to be able to speak to so many people about MS. For someone who's been living

with MS for so many years, I still don't feel there is enough awareness about this disease. I love that I am able to share my experience and help people be aware of what MS is.

For all the people who would love to get involved and fundraise for Kiss Goodbye to MS, you really don't need to be experienced in fundraising. You just need to come up with an idea (new, old or re-invented!), find the right support and put in the time to make it work!

Whether you choose to run in a fun run, host a bake sale, shave your head or put on a garage sale, you have the power to be as creative as you like! If you're thinking of

putting together an event like me, my best suggestion would be to set a fundraising goal and speak to the Kiss Goodbye to MS team! Know how much you would like to raise so that your supporters also know and can help you achieve it! Give yourself enough time to put the event into action. Most importantly, have fun with it! It never feels like hard work when you enjoy what you're doing, especially for a cause you're passionate about.

My teacher has been very supportive from the start and it helps to have someone there who is also excited and enthusiastic about putting together this event.

I hope that one day there will be a cure for MS!

I encourage you to get in touch with Kiss Goodbye to MS on **1300 785 717** to learn more about how to put on a successful fundraiser or if you've got an idea and are ready to get started, sign up by visiting **kissgoodbyetoms.org** and create your fundraising page!



Cathy Aitken (bottom left), host of a Kiss Goodbye to MS ballet class fundraiser with participating community members



“

It's not something that comes up in conversation every day, but it should be, says George Saliba of leaving a gift in his Will.

”

Transforming lives through future research

Include a Charity Week, is an awareness initiative encouraging more Australians to consider leaving a gift in their Will.

George Saliba is one of our many supporters remembering MS Research Australia in his Will. George has secondary progressive MS and was diagnosed over 20 years ago, “fortunately for me it’s been quite stable for a number of years now”, he says.

“When you’re first diagnosed you feel isolated even while you are surrounded by family and friends. When you reach out and find MS Research Australia, you become part of an organisation, which has the same purpose as you.”

George’s motivation to support MS Research Australia was driven by knowing what it is like to live with MS and by meeting many inspirational researchers who are dedicated to stopping and reversing the effects of MS.

“What really brought it to the forefront was the passing of my mother over four years ago”, George adds, “it got me thinking about leaving something that would benefit future generations.”

You too have the power to change the future for the next generation

George says, “It would be lovely to find the cure in my lifetime but if it isn’t found, then let’s hope it happens in somebody else’s lifetime. MS is completely different today than it was when I was diagnosed 20 plus years ago – the difference in that

period of time is massive, and I believe all the research into MS that has happened in that time, has made this happen.”

MS Research Australia CEO, Dr Matthew Miles agrees that research is fundamental, “MS is a complex, confusing and confronting disease that takes a toll on those living with the disease, their families, friends and carers. In such a short amount of time, we’ve seen remarkable progress for the majority of people living with MS and this will exponentially increase over the next 5 years. Our goal is to ensure that everyone living with MS benefits from this incredible progress and not just some.”

Gifts in Wills are left by people from all walks of life and no matter how large or small the gift, it will drive the acceleration of MS research locally and globally for generations to come.

How to leave a gift in your Will

There are a few types of gifts in Will you can leave, but most typically people leave a **residual** or **percentage** gift. This type of gift is flexible as you can allocate a share of your estate to MS Research Australia alongside catering for loved ones without having to know what your overall estate will be worth.

Alternatively, you can consider leaving a specific gift, which is a specified sum of cash or asset which you own.

Unfortunately gifts of these nature lose value with inflation.

Leaving a gift in your Will is a very personal decision. We encourage you to advise your loved ones of your intent and consult a solicitor when writing or editing your Will. “My friends and family were very proud as it wasn’t something they had thought about”, says George of leaving his gift.

When the time is right, we’d like you to consider leaving a gift in your Will. Your gift will have a lasting impact and continue transforming the lives of people with MS.

“The feeling you get is very fulfilling and gratifying, so if you can, just do it”, George says, “it will be my legacy, knowing I’ve gifted this in my Will and this will help others when I’ve passed on...it’s a pleasing feeling.”

We'd love to hear from you

If you have already remembered MS Research Australia in your Will, we’d love to thank you personally. Alternatively, if you would like to receive further information about leaving a gift, please get in touch.

For a friendly chat, please contact Neil Robertson, Planned Giving and Relationship Coordinator, on **1300 356 467** or send an email to bequests@msra.org.au

LIVE Update.

Register Now – Live Update 2019

We're excited to announce that registrations for our Progress in MS Research Live Update 2019 are now open!

Join us in cyberspace from 10am on Saturday 2 November to hear the latest MS research news direct from the experts.

Topics will include modifiable lifestyle factors, myelin repair, integrating patients with research and more.

REGISTER for the Live Stream now at msra.org.au/events/liveupdate2019

DATE: Saturday 2 November 2019

TIME: 10am – 11am (AEDT)

LOCATION: Live stream on your PC or mobile device

COST: FREE

Our internationally renowned expert speakers include:



**Associate Professor
Ellen Mowry**

John Hopkins University,
USA

Associate Professor Mowry focuses on environmental factors that influence the risk and prognosis of MS. Her major work identified the link between Vitamin D status and relapse risk in people with MS. Associate Professor Mowry also conducted the first study comparing gut bacteria in people with MS and without MS. She designs and conducts clinical trials in MS and is working on refining personalised therapy for people with MS.



**Associate Professor
Gonçalo Castelo-
Branco**

Karolinska Institutet,
Sweden

Associate Professor Castelo-Branco's research focuses on myelin-producing cells and how changes in gene activity that are not caused by changes in the DNA sequence occur in these cells. The overall aim of his research is to design therapies based on these changes in gene activity to induce myelin repair in demyelinating diseases, such as MS.



**Professor Tanuja
Chitnis**

Brigham and Women's Hospital, USA

Professor Chitnis focuses on moving laboratory discoveries to clinical trials for MS and related diseases. She also focuses on sex differences in autoimmune disorders and paediatric MS research. She oversees a team of researchers working to understand the causes, differences and responses to treatment in people with MS, and is investigating why MS progresses differently among people to inform new treatments.

HELP MS RESEARCH AUSTRALIA FIND A CURE FOR MS

Donate (Donations over \$2 are tax deductible)

To support MS Research Australia's vital work I would like to:

- Make a one off donation of \$
- Make a monthly donation of \$
- Learn more about leaving a gift in my Will
- I have already left a gift in my Will to MS Research Australia

Contact details

Title: First name:
 Surname:
 Address:
 Suburb: State: Postcode:
 Phone: Mobile:
 Email:

Payment method:

Cheque (made payable to MS Research Australia)
 Direct Debit Request (copy of service agreement can be provided on request)
 Financial institution: ABN 34 008 581 431
 BSB number:
 Account number:
 Account holder's name:
 Credit Card
 Mastercard Visa Amex
 Credit card number:
 Exp: CVV:
 Name on card:
 Signature:



RESEARCH
AUSTRALIA

ABN 34 008 581 431

REGISTERED
CHARITY

