

NEWS OF THE ME RESEARCH YOU ARE HELPING TO FUND

breakthrough

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Breakthrough magazine is published by ME Research UK, a Scottish Charitable Incorporated Organisation with the principal aim of commissioning and funding high-quality scientific (biomedical) investigation into the causes, consequences and treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). The charity also aims to energise ME research by identifying potentially important areas for future biomedical research, and producing high quality professional reviews and reports. *Breakthrough* is an open access publication and, apart from images and illustrations, the content may be reproduced free of charge, subject to the terms and conditions found at meres.uk/bt-terms.

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In the spotlight

What's happening in the world of ME research and funding

Editorial

As I write, we are all living through a situation unprecedented in living memory. For now, enforced isolation and the inability to engage in 'normal' activities has become the new normal. We all hope that science will ultimately deliver a better understanding of the COVID-19 virus, leading to improved treatments for those severely affected, and ultimately a vaccine.

This year marks our twentieth anniversary, and we are as committed as ever to inform, influence and invest in rigorous science, ultimately to make a tangible difference to the lives of everyone affected by ME. We are in the very fortunate position to be well funded presently and, having recently put out a call for both research applications and PhD studentships, are actively seeking out opportunities to carefully invest the funds you have entrusted us with. We talk in more detail about our strategy going forward on page 11.

We are delighted to welcome two new members of the ME Research UK team. Dr Eleanor Roberts has joined the Board as a Trustee, and Dr Louise Crozier has joined the staff as our Sci-

ence & Engagement Director. You can find out a bit more about them both on page 15.

As ever, this issue of *Breakthrough* provides a round-up of research across the globe, including antibody research we funded carried out by Prof. Scheibenbogen and her team in Berlin, as well as other recent studies.

We also wanted to highlight the fantastic work being done by Natalie Boulton and Josh Biggs on their series of videos 'Dialogues for a Neglected Illness'. The first five videos from a planned series of around twelve are now available online, and the article on pages 4 and 5 gives more details.

Although fundraising and events generally are curtailed at present, we have highlighted some wonderful recent fundraising stories on pages 20 to 22. A big thank you to everyone who is supporting biomedical research into ME and has raised funds for us. Without your support and donations, we would not be able to fund as many studies as we do.

Thank you, and I hope you enjoy this issue of *Breakthrough*.

Jonathan Davies
Chair, Board of Trustees

Voucher Codes

ME Research UK is one of four charities competing in the 'My Favourite Voucher Codes' ballot during May, the winner receiving a donation of 20% of the site's profits during that month.

You can find full details on our website (meres.uk/voucher), but all you need to do is visit bit.ly/2VKnuw6, select ME Research UK from the list of charities on the right-hand side, and click 'Vote'.

Voting is free and you do not need to use any codes or sign up to the site for your vote to count.

Shopping at Amazon

If you're like us, you will be making full use of online shopping during this time when visiting most bricks-and-mortar shops remains out of the question.

We would certainly encourage you to support independent local businesses, many of who now deliver or who have online ordering. But sometimes it just has to be Amazon.

As a bonus, you can also support ME Research UK every time you shop at amazon.co.uk. And the best thing is that it doesn't cost you a penny more!

There are two ways to help:

- Go to amazon.co.uk via the button on our website, or
- Login to Amazon Smile via meres.uk/smile, and select ME Research UK as your charity.

When you shop – they'll donate!



Dialogues for a Neglected Illness

New series of videos available online

A valuable new resource is currently being developed by filmmakers Natalie Boulton and Josh Biggs, with the help of an award from the Wellcome Public Engagement Fund.

Dialogues for a Neglected Illness is a series of videos addressing different aspects of ME/CFS, including its diagnosis, management, treatment and patient experiences.

The final project will comprise a website containing around a dozen short videos, including interviews with – and input from – doctors, researchers, patients, carers and advocates. All the videos are produced to a very high standard, with contri-

butions from some of the leading lights in ME research. Each is also accompanied by educational materials and references, and the series is available to watch at dialogues-mecfs.co.uk.

There is a wide range of contributors, including such names as Dr Eliana Lacerda, Prof. Jonathan Edwards, Prof. Mark VanNess, Staci Stevens and Dr David Systrom, as well as people with ME/CFS and patient advocates.

The goal is “a resource which patients can use to help their doctors and other health, education and research professionals understand more about this disease and the issues faced”.



There are currently five videos available to watch: an Introduction to ME/CFS, Understanding Post-exertional Malaise, a Quick Guide to Post-Exertional Malaise, and two films on Understanding Graded Exercise Therapy, including discussion of the controversial PACE trial. In addition, a video on Severe ME is coming soon.

All are available on our website (meres.uk/dialogues), and are also being streamed on the project's website as well as a number of other places.

More videos on other topics will be made available over the course of the year, culminating in a live event with video screening, speaker and Q&A session which is currently scheduled for some time in 2021.

CMRC Conference 2020

Meeting attracts leading ME researchers

The sixth annual CFS/ME Research Collaborative (CMRC) conference was held in Bristol on 10 and 11 March, 2020.

The developing coronavirus situation meant that many people were not able to attend because of travel restrictions and health concerns. However, despite these potential limitations, the event still attracted many leading ME/CFS researchers and influencers.

Speakers included Prof. Alain Moreau from Université de Montréal, Prof. Chris Ponting from the University of Edin-

burgh, and Richard Morley and Rachel Marshall from the Cochrane Library.

The varied programme of presentations and workshops was introduced by Prof. Stephen Holgate, Chair of the CMRC. ME Research UK's newest trustee, Dr Eleanor Roberts, attended the two-day event on our behalf, and took advantage of the opportunities to meet with potential research partners and past funding recipients.

Most of the talks are now available to watch for free on YouTube (bit.ly/2JT7v9i).



The Countess of Mar

On 1 May 2020, the Countess of Mar retired from the House of Lords after almost forty-five years of service.

The ME community will have lost a valued champion and campaigner for those affected by ME, but we know that she will not be withdrawing from the fight for those with ME/CFS, and ME Research UK is truly grateful for all that she has done so far.

There will be a full appreciation of her work in the next issue of *Breakthrough*.



All-Party Parliamentary Group on ME

New group set to discuss biomedical research spending

Almost a year after the House of Commons Debate on ME, a new All-Party Parliamentary Group (APPG) on ME was formed on 14 January 2020, thanks largely to the efforts of Carol Monaghan MP (pictured right).

Although APPGs are informal, cross-party groups with no official status, they exist to allow campaign groups, charities and other non-governmental organisations to meet with interested parliamentarians, with the aim of informing and influen-



cing decision-making.

Biomedical research spending by the Medical Research Council (MRC) and the National Institute for Health Research (NIHR) is one of the topics of interest highlighted by the twenty-four MPs who joined the APPG on ME.

Carol Monaghan was elected Chair, with Sharon Hodgson and Stephen Metcalfe as Co-Chairs, and a list of Officers can be found on Parliament's website (bit.ly/2XCDPW9).



IBS study update

Project cancelled due to staffing problems

In 2018, we announced a newly funded project led by Prof. Yan Yiannakou of Newcastle upon Tyne Hospitals NHS Foundation Trust, looking at the link between irritable bowel syndrome (IBS) and ME/CFS, and investigating immune activation and the gut microbiome in patients with these conditions.

However, it is with great re-

gret that Prof. Yiannakou has had to cancel the proposed research. Unfortunately, and despite his best efforts at finding a solution, staff changes in his department mean that the project is no longer feasible, although we hope it might be possible to reignite this promising line of research at some point in the future.

The Big Give

The Big Give organises the UK's biggest match-funding campaign, the Christmas Challenge, which runs for seven days from 2 December 2020.

The campaign offers supporters of participating charities the opportunity to have their donations doubled or even quadrupled, and it is a fantastic chance to maximise the value of donations and the benefits of giving. For the campaign to work, we need pledges.

Companies and individuals can pledge a minimum of £100 in matched funding, which is then called upon when donations are made through the Big Give website (thebiggive.org.uk). If we are lucky, a Big Give Champion will match the donations and the pledged amount.

Please contact us if you would like to learn more about the Big Give, or how you or your company/employer could help.



Message received?

New research from Germany looking at the effects of **immunoglobulin on adrenergic receptor activation**

The immune system is a fertile area for research in ME/CFS, and a number of recent and ongoing studies funded by ME Research UK have been exploring various aspects of abnormal immune function in the illness.

This includes work carried out by Prof. Carmen Scheibenbogen and her team at the Institute for Medical Immunology in Berlin, and the first results from their research were recently pub-

lished in the journal, *Brain, Behavior, & Immunity – Health*.

Immunoglobulins

Immunoglobulins (also known as antibodies) play a key role in the immune system. They are proteins produced by the white blood cells which recognise and attack harmful invaders such as bacteria and viruses.

Some immunoglobulins (autoantibodies) are directed against the body's own proteins, cells or tissues, which can lead to

the development of a so-called autoimmune disease such as multiple sclerosis or lupus.

Some recent research suggests that these immunoglobulins may also have a role in ME/CFS, at least in some patients.

In 2016, Prof. Scheibenbogen's team found that nearly a third of ME/CFS patients they studied had increased levels of autoantibodies directed against adrenergic receptors. These receptors are involved in the sympathetic nervous system, and are

“Targeting of the adrenergic system has potential as a treatment”



Prof. Carmen Scheibenbogen (second right) and her team

found in many cells of the body, including immune cells.

In their current study, the group wanted to look in detail at the effects of immunoglobulins on adrenergic receptors and on immune function in ME/CFS.

The researchers obtained blood samples from five ME/CFS patients with increased levels of autoantibodies against adrenergic receptors, from five ME/CFS patients with normal autoantibody levels, and from six healthy control subjects.

In the first part of the experiments, immunoglobulin isolated from these samples was added to cells containing adrenergic receptors, in order to assess whether or not the receptors became activated as a result.

In the second part, the immunoglobulin was added to immune cells (specifically, white blood cells called monocytes) to

see if this altered their function.

Receptor activation

Firstly, immunoglobulin from healthy control subjects activated the adrenergic receptors (as demonstrated by a change in signalling), and there was a similar result with immunoglobulin from ME/CFS patients with normal autoantibody levels.

In contrast, there were no such effects when using immunoglobulin taken from patients with increased autoantibody levels.

Secondly, immunoglobulin from healthy controls also had an effect on immune cell function, by inhibiting the production of cytokines and T-cells.

Immunoglobulin from patients with increased autoantibodies had no such effect, while there was a modest effect using immunoglobulin from those with normal levels.

How can we summarise these fairly complex results, and what do they mean for patients with ME/CFS?

The key finding of this study is that, in a subgroup of ME/CFS patients with increased autoantibody levels, the activation of adrenergic receptors by immunoglobulin is lower than normal. This suggests that many of the symptoms of the illness – such as immune activation and autonomic abnormalities – may be mediated or made worse by dysfunction of these receptors.

The authors suggest that targeting of the adrenergic system may therefore have potential as a treatment for ME/CFS. However, this goal could be a long way off. In the meantime, we look forward to the continuation of this research by Prof. Scheibenbogen and her team as they explore the area further.

The way ahead

ME Research UK's plans for the next five years to **inform, influence and invest** in ME research





Bob and Vance at our tenth anniversary celebration in 2010

How it all began

ME Research UK – or the ME Research Group for Education and Support (MERGE), as it was originally called – was established by Dr Vance Spence and Robert McRae in 2000, thanks to the impetus and financial backing of Founding Patron, Roger Jefcoate DL CBE.

The charity's mission was to fund high-quality scientific (biomedical) research into ME/CFS, and to provide information about research which was accessible to as diverse an audience as possible. They realised that only through high-quality research would the illness be understood and, eventually, a cure found.

Vance and Bob were diagnosed with ME/CFS in the 1980s and 1990s, respectively, and they shared a vision and a desire to ensure that more research into the illness, which so affected their lives, could be car-

ried out and the results better understood.

From the outset, each brought their own professionalism to the fledgling charity and their legacy imbues our work today. Vance, as a leading research scientist at the University of Dundee, ensured that rigorous science was at the core of the charity. Bob, a senior banker with Clydesdale Bank, created the structures that allowed ME Research UK to operate with utmost probity and financial security.

Both Bob and Vance knew that only solid research would change the prevailing attitude of scientists and the medical community to the illness. This research had to be sound, and researchers and supporters had to trust the charity financially. Scientific rigour and financial probity are therefore the twin

strands that thread through our organisation, and could be said to be the DNA that made us the charity we are today.

Of course, Vance, Bob and Roger are not alone in being pivotal to the growth of the charity – Betty McRae was a long serving and highly valued Trustee and also our Founding Ambassador, while Dr Neil Abbot, our Research & Operations Director, was the core of the charity for many years, writing *Breakthrough* magazine and establishing close ties with researchers worldwide.

However, what we achieved and how we will continue to deliver on our mission is due to our supporters. It is thanks to your generosity that we have funded all our work so far, and how – with your continued support – we intend growing into the future.

Our plans for the future

Over the past months, we have reviewed our previous work and looked closely at the wider ME/CFS research environment. This has enabled us to shape our priorities for the coming years and form our strategic plan.

This plan is designed to maximise our available funding, and help us deliver our mission of informing, influencing and investing in ME/CFS research worldwide, ultimately to end the suffering caused by ME/CFS.

We want to achieve ambitious goals that we believe are key to understanding the causes and consequences of the condition, as well as identifying potential treatments. There are four areas of focus:

Science

We will establish ME Research UK as a leading expert on ME/CFS biomedical research by:

- Proactively funding biomedical research;
- Working collaboratively with other institutions and organisations to influence the biomedical research agenda;
- Taking a leading role in interpreting, analysing and commenting on published biomedical research in a way that can be understood by a range of audiences; and
- Developing key criteria that can provide funding at all levels, including students, research teams and fellows.

Awareness

We will ensure that ME Research UK has a growing base of engaged supporters covering various communities by:

- Ensuring our brand is recognised by a range of audiences; and
- Undertaking activities that raise awareness of ME/CFS and our work across all relevant audiences.

People

We will ensure that employees and volunteers are the best available and are supported to give of their best by:

- Recruiting volunteers throughout the UK; and
- Reviewing our current structure, and investing in the best people to achieve our goals.

Funding

We will maximise the funding available to ME Research UK for biomedical research by:

- Increasing the amount of money we spend on research;
- Securing funding from a wider range of sources; and
- Controlling non-research costs and maintaining financial discipline.

Our five-year plan is ambitious, but we believe that robust biomedical research is the only way to understand ME/CFS. We will continue to work to achieve our vision.

We believe that our strategy will build on the work of the past twenty years, maintaining our focus on funding the best biomedical research, while committing resources to informing as many people as we can about the condition and the need for more research, and influencing others to join us in investing far more funding into ME/CFS research.

Since embarking on our strategic plan, we have already undertaken a number of activities to help us to achieve our goals. We have:

- Recruited a Science & Engagement Director to help us fund researchers and encourage collaboration between institutions and others;
- Published a global call for applications encouraging researchers to submit research proposals to us;
- Published a global call for PhD studentships to encourage universities to apply to us for funding for ME/CFS PhD placements;
- Promoted volunteering opportunities to seek new ambassadors and community fundraising champions throughout the UK; and
- Started a review of our marketing and branding to ensure we are communicating in the most appropriate way to our supporters, while also looking at how we can reach a much wider audience.



How to help build our future

ME Research UK's exciting plans for the next few years have been made possible largely through the generosity of funds from bequests and family trusts.

By remembering ME Research UK in your Will, you can give a gift that costs nothing to make now, but could transform the ME/CFS research landscape and help play a vital part in changing the understanding of ME/CFS far into the future.

When the time is right for you – and you have made provisions for those closest to you – leaving a gift in your Will to us will ensure that your hopes and wishes will live on through ME Research UK.

Every gift in every Will makes a difference to us, whatever its size. You can simply make your bequest to ME Research UK or choose to specify

that your gift be used for research specifically. Gifts with no restrictions help us invest in our work where we know the need is the greatest, whereas a bequest specified for research will only be used to fund biomedical research.

Our website has information on how to leave a gift to us in your Will, and can also help with wording.

Through *Breakthrough* magazine we reach out to supporters to mobilise their contacts to assist us. There are many companies and individuals who can help make research happen but do not know about the work we do or how to help. This can range from ME Research UK being nominated and chosen as a company's featured charity, matched sponsorship for employee fundraising activities, or

even being a Pledger in the 2020 Christmas Big Give.

The Big Give runs the UK's biggest match-funding campaign, the Christmas Challenge, and offers supporters of participating charities the opportunity to have their donation doubled or even quadrupled. You can read more about The Big Give on page 7 of this issue.

Of course, many supporters wish to make regular donations every month. If you give to us regularly we can plan future projects and work of the charity knowing that we have a secure base. We never agree to fund research until we have the money available, and so having a regular income lets us invest more in our work. You can make a regular donation via the form on the inside back cover of *Breakthrough* or on our website.

Dr Louise Crozier

Meet our new colleague

I am delighted to join ME Research UK as Science and Engagement Director, and excited to take on the challenge of identifying key areas of research that deserve more funding.

My background is in molecular microbiology, where I worked on significant issues facing the world today, such as food waste, foodborne disease and preventing exposure to pathogenic microbes. My PhD was on food poisoning bacteria such as *E. coli* and *Salmonella*, and I studied gene expression changes in these bacteria, and helped identify key changes in metabolism that help them survive on food products and cause disease.

I then worked in industry for several years, helping to trial a new technology for reducing microbes in different environments. During that time, I developed the science programme for the company, and regularly gave presentations communicating complex science for many different audiences. In my spare time, I volunteer as a STEM Ambassador, helping to inspire young people to pursue a career in science.



I am looking forward to getting involved in the world of ME research, engaging with researchers worldwide and helping communicate key findings in the science, as well as promoting the importance of research into ME.



Dr Eleanor Roberts

Our newest Trustee

We were very pleased to welcome Eleanor to the Board of ME Research UK as a Trustee earlier this year.

Eleanor has a strong background in biomedical research, including a PhD in HIV neuropathology, and has built a successful career as a science writer. As someone living with ME, she also brings that insight and understanding of the illness which, when combined with her significant research experience and expertise, further strengthens our scientific capability.

Within days of becoming a Trustee, Eleanor attended the CMRC conference on our behalf, and her knowledge and perspective have already proved invaluable.

Research bites

Our round-up of recent research from around the world

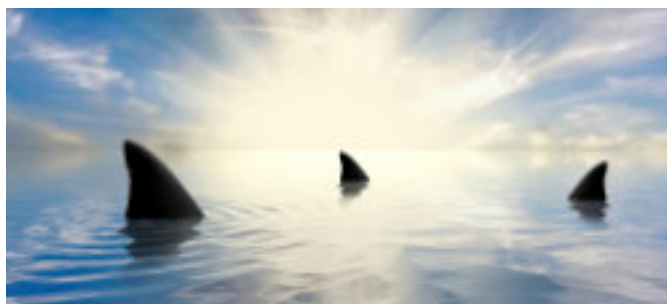


Intra-brainstem connectivity

Barnden et al., NeuroImage: Clinical, 2019

Functional connectivity describes the links that exist between different regions of the brain, and which allow information to be processed. Activity occurring in two regions of the brain at the same time suggests a connection between those regions – either a direct pathway or an indirect cause-and-effect. Last year, researchers in Melbourne, Australia published results from their ME Research UK-funded study looking at functional connectivity in adolescents with ME/CFS. Another Australian group has also recently investigated this area, assessing connectivity in various regions of the brainstem in people with ME/CFS, at rest and while performing tests of attention and concentration.

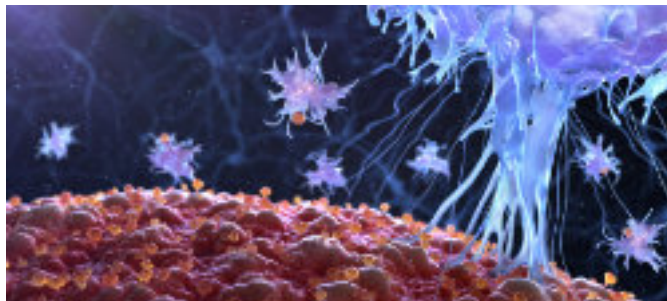
Deficits in intra-brainstem connectivity were found in the ME/CFS group, but only while performing cognitive tests. Specifically, connectivity was reduced between the medulla (autonomic function) and midbrain (motor function, and auditory and visual processing) within the brainstem, and between the brainstem and other parts of the brain. The authors conclude that deficits in brainstem connectivity may help explain some of the autonomic changes in ME/CFS, as well as impairments in attention, memory, cognitive function and other symptoms. There is a long history of reports of brainstem abnormalities in ME/CFS, so it is good to see research continuing in this area.



Natural born killers

Eaton-Fitch et al., Systematic Reviews, 2019

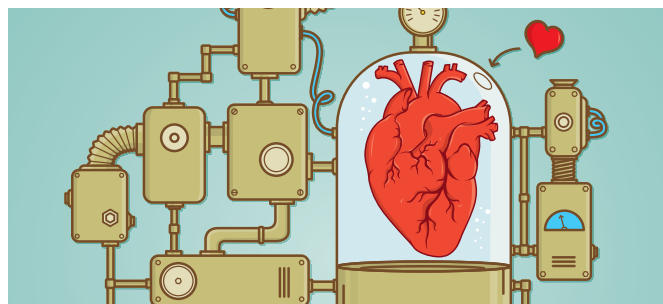
Despite their dramatic name, natural killer (NK) cells are actually an important part of our immune system and help protect us from viruses by killing cells that have been infected. A systematic review of seventeen studies confirmed that NK cytotoxicity (their ability to destroy other cells) is consistently compromised in some ME/CFS patients, compared with control subjects. This suggests they may be less able to fight off infections, but also that NK cytotoxicity may represent a biomarker that could help define a subgroup of ME/CFS patients.



T-cell metabolism

Mandarano et al., J Clinical Invest, 2020

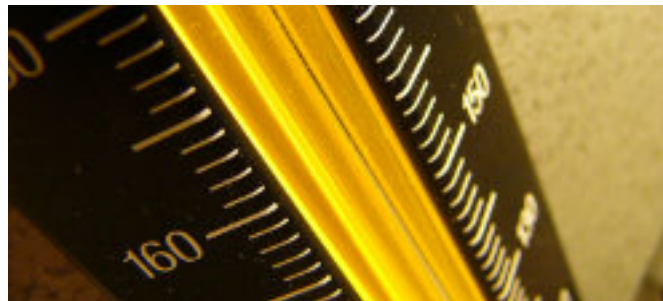
Helper and killer T-cells are white blood cells involved in the immune response to infection. Helper T-cells assist other immune cells, while killer T-cells destroy infected cells and tumours. A recently published study has found that there are abnormalities in the metabolism pathways of these types of T cells in patients with ME/CFS. Specifically, glycolysis was reduced in both types of cell while at rest, and also in killer T-cells when activated. These alterations in metabolism are consistent with other findings suggesting that immune function is dysfunctional in ME/CFS patients.



Heart regulation

Nelson et al., Medicine, 2019

Another recent systematic review has provided “evidence of altered cardiac autonomic regulation in ME/CFS”. Cardiac autonomic regulation refers to the body’s system that controls the functions of the heart, such as heart rate. Combining the results of multiple studies, various measures of heart rate under different conditions (e.g. at rest and during exercise) were abnormal in ME/CFS patients compared with controls, confirming the altered autonomic cardiac function that has also been reported in previous studies funded by ME Research UK.



A cause of blood pressure problems?

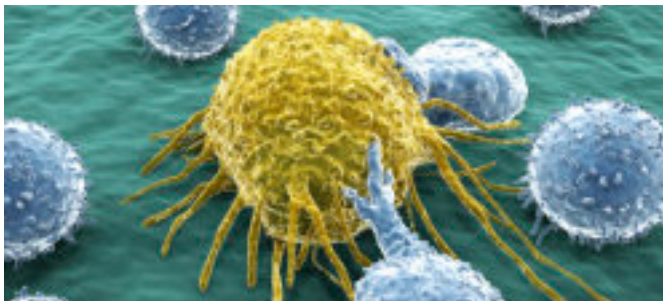
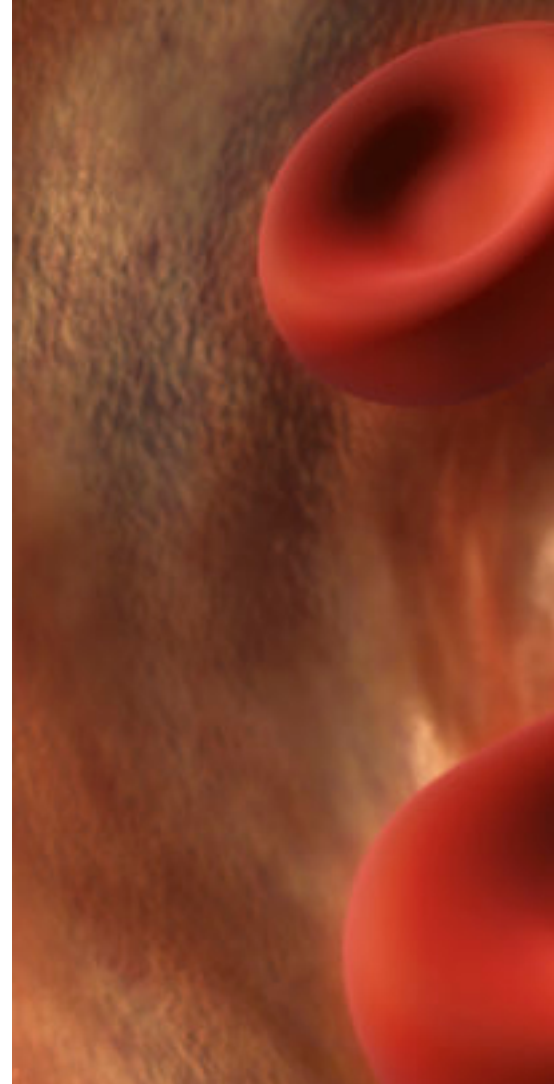
Germain et al., Metabolites, 2020

Plasma is the fluid component of blood which contains many important substances. Researchers from Cornell University analysed plasma from 52 women, equally split between ME/CFS patients and control subjects, and found that a group of compounds linked to blood pressure, called acyl cholines, were decreased in the patients. The authors suggest that a decrease in these acyl cholines – and downstream pathways – could help explain some common ME/CFS symptoms associated with the regulation of blood pressure, such as dizziness, blurred vision and fainting.

Factors in the blood

ME/CFS Research Review, 2019, bit.ly/2UbydyI

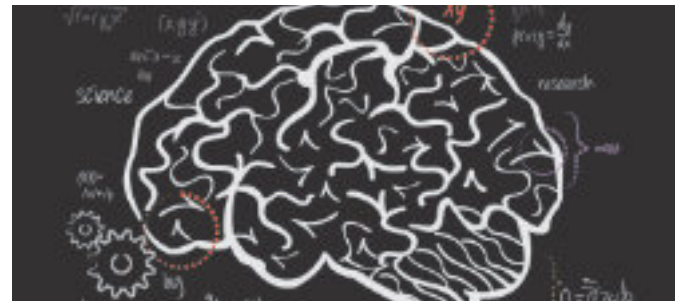
The central hypothesis of Stanford researcher, Dr Ron Davis, is that some factor in the blood plasma of ME/CFS patients is driving their illness. In previous experiments, the electrical impedance of a sample of white cells in plasma from ME/CFS patients increased when stimulated with salt, while there were no electrical changes in samples from healthy volunteers. But these changes in impedance disappeared when the ME/CFS cells were placed in plasma from healthy people, suggesting that something in the ME/CFS plasma is making the cells act abnormally. The dramatic difference between ME/CFS and healthy plasma suggests this test might be useful as a biomarker, but the results may also lead to discoveries about the pathology of the illness. Dr Davis has seen that red-blood-cell deformability is reduced in samples from ME/CFS patients, but only when the cells are tested in patients' own plasma, and he has also found that the rise in impedance in ME/CFS white cells seen in the salt tests can be prevented by adding the mitochondrial antioxidant SS-31 or the multiple sclerosis drug copaxone. Ongoing experiments are looking at whether the offending factor is some form of virus, bacteria, fungus or parasite.



Promising new biomarkers

Missailidis et al., Int J of Molecular Sci, 2020

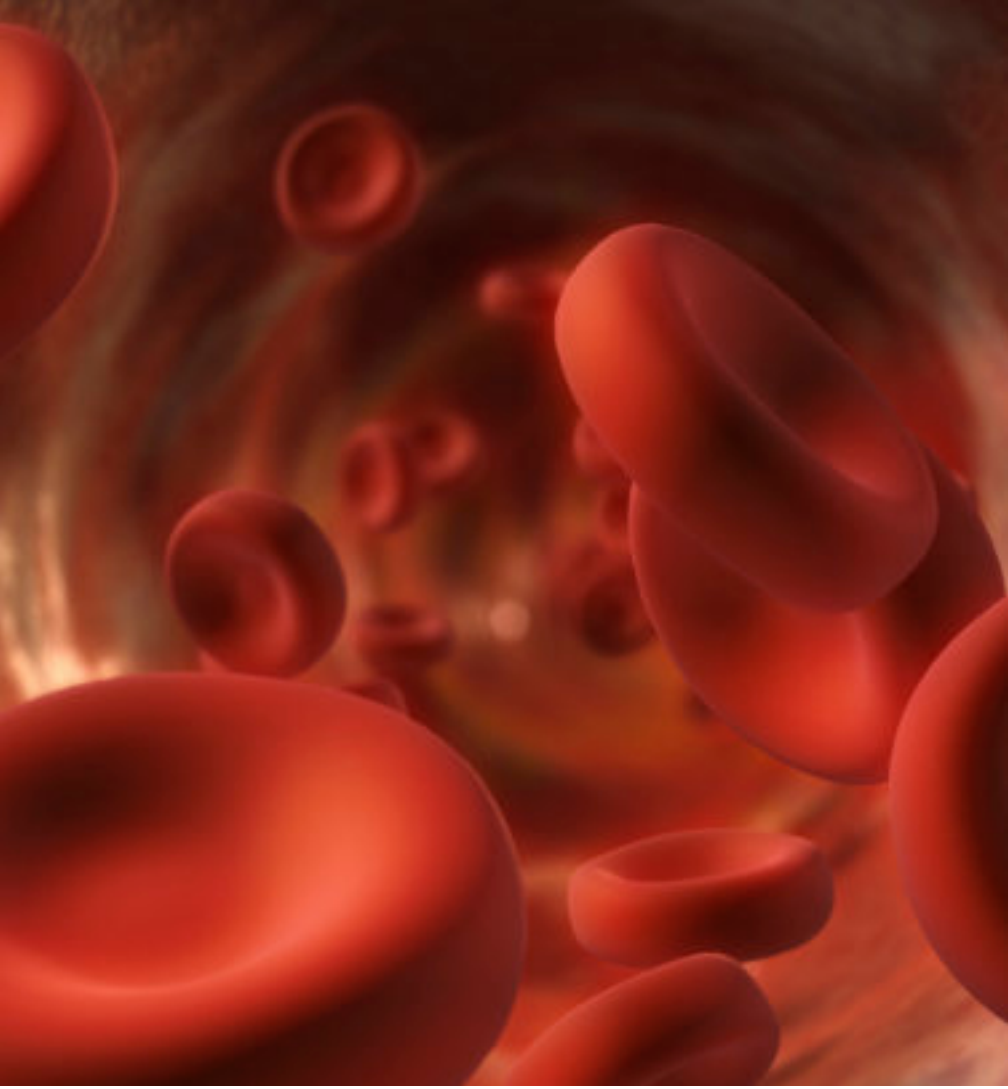
Scientists from Melbourne previously reported that white blood cells (lymphocytes) extracted from ME/CFS patients died faster than normal after having been frozen. They also found abnormalities in mitochondrial respiratory function and a protein called TORC1. The authors now suggest a two-step protocol using these tests as a biomarker: a blood test for lymphocyte death rate 48 hours after freezing, followed by confirmatory tests of TORC1 and respiratory function, if needed. Together, these tests showed promise in distinguishing cells from ME/CFS patients and healthy controls.



Brain blood flow

Van Campen et al., Clin Neurophys Pract, 2019

The head-tilt test is used to measure changes in heart rate and blood pressure while patients are gradually tilted into an upright position. By combining this approach with Doppler imaging to measure blood flow to the brain, researchers from the Netherlands found that most ME/CFS patients they studied (including those without blood pressure problems such as POTS or delayed orthostatic hypertension) had reduced cerebral blood flow during this test. These results suggest that the protocol may be an option for use as a tool in the diagnosis of ME/CFS.



“Some factor in the blood plasma of patients [may be] driving their illness”



POTS and autoimmunity

Gunningill et al., JAHA, 2019

Many people with ME/CFS have postural orthostatic tachycardia syndrome (POTS), which is characterised by large changes in heart rate on standing, leading to a number of symptoms. New research suggests that POTS is an autoimmune disorder – that is, it stems from the body being mistakenly attacked by its own immune system. Among 55 patients with POTS, the majority had raised levels of autoantibodies targeted on autonomic receptors. This suggests that existing medications targeting the immune system could therefore be an effective treatment for some patients.



Endothelial dysfunction

Scherbakov et al., ESC Heart Failure, 2020

The endothelium – the inner lining of the blood vessels – has been the focus of some of the research we have supported over the years. Endothelial dysfunction is a serious cardiovascular risk factor, but is also common in many autoimmune diseases. In a recent study, researchers from Berlin found that ME/CFS patients with endothelial dysfunction also had higher disease severity, with severe immune symptoms recorded. The authors suggest that endothelial dysfunction may be a marker to assess the potential risk of cardiovascular issues in ME/CFS patients in future clinical trials.



Friends united

Recent fundraising activities by our supporters. To support ME Research UK and raise funds for ME research, please visit our website for ideas.

Coastal run

While the rest of us resolved to stop smoking, read more or finally get round to painting the garage this year, Tabitha Angle-Smith had grander plans for 2020. Inspired by a friend who was a runner before getting ME, Tabitha challenged herself to make the epic 1,400-km run round the Wales Coast Path, all in aid of ME Research UK. She has already completed the first stage, 126 km from Chester to Bangor, which she ran over three

days in January, and had begun the 215-km leg from Bangor to Anglesey before injury meant she had to postpone. You can contribute to this fundraiser by searching for 'Tabitha Angle-Smith' on [JustGiving.com](https://www.justgiving.com). Diolch yn faw, and lwc dda, Tabitha!

Swing with ME

Our congratulations and thanks to Abbie & Debbie Grant and everyone else involved in making last year's Swing with ME event

such a success. Nearly two hundred people came through the doors of Titchfield Community Centre on 31st August 2019 for an evening of music, dancing and laughter. The evening was organised to raise awareness of ME, and the team made a fantastic total for ME Research UK. The event featured music from the forties, fifties and sixties, as well as a live performance by the Muskrats. By all accounts, everyone enjoyed an amazing night of music and dancing.



01



02

Welsh duathlon

Wales was also the location for Mair and Owen Squire's fundraising efforts this March, as they cycled and ran in the Wildflower Duathlon at The National Botanic Gardens of Wales. The duo had also planned to compete in the Mumbles Duathlon on 21st March, but, regrettably, like many other sporting events this year, the race had to be postponed until a later date. Mair and Owen were competing in aid of ME Research UK, and in



03

support of their friend's fifteen-year-old son who is affected by ME. "At a time when he would be exploring and finding his passions and interests, this high achieving chap struggles to function and is virtually house-bound." Many thanks to Mair and Owen and all who supported them in their amazing feat. Thanks also to Melissa Davies whose Cake and Coffee fundraiser at the Tree House, Aberystwyth helped swell the coffers.

01 Tabitha Angle-Smith well on her way around Wales

02 A hall full of swinging supporters

03 Alice Hodcroft celebrates an impressive time in the Great North Run

Super Sunday

Sunday 8 September 2019 was a busy day for our supporters. Our thanks to Alice Hodcroft, Elizabeth Tabor and Arun Choudry who completed the Great North Run; Louise Dykes who tackled the Bournemouth International Triathlon; and Mary MacLellan who spent nearly ten hours on her bike in Pedal for Scotland. Let us hope that the coronavirus situation is under control in time for another Super Sunday this year.

Priest of Love

Screening of classic British film in memory of Sophie Miles

Towards the end of 2019, our CEO, Simon Phillips, attended a special screening of the 1981 film *Priest of Love* at the Rex Cinema in Wareham, Dorset as part of the Purbeck Film Festival. The screening was arranged by the film's director, Prof. Christopher Miles, and his wife Suzy, in memory of their daughter Sophie. Due to her symptoms and health issues, Christopher and Suzy chose ME Research UK as the charity they wished to support.

Priest of Love concentrates on the latter part of the life of novelist D H Lawrence, and the cast includes many familiar actors such as Sir Ian McKellen (in his first film role), Dame Janet Suz-

man, Sir John Gielgud, Dame Penelope Keith and Ava Gardner. It was directed and produced by Christopher, and filming took place at many of the actual locations where Lawrence had lived, worked and visited.

As part of an enjoyable evening, Simon gave a talk about ME

and our work, and this was followed by an extremely entertaining and informative Q&A with Christopher, Dame Janet and Andrea Etherington.

Sophie's story is sadly all too familiar, as she struggled to get a diagnosis from her GP and was advised that her condition was psychological and given medication. Sophie eventually worked out her own way of managing her symptoms, and was able to live a more active life until she was diagnosed with cancer in 2018. Sadly, Sophie passed away later that year.

We are very grateful to the Miles family, Dame Janet and all those who attended the event. The Sophie Miles Bequest will be used to support ongoing research into ME/CFS.



Our CEO, Simon, with **Christopher Miles** before the screening



Christopher, Sophie and Suzy Miles at the London premiere of *Priest of Love*



Q&A with **Dame Janet Suzman, Andrea Etherington** (Purbeck Film Festival) and **Christopher Miles**

Standing Order Form

To support our work, please consider setting up a standing order by completing this form and sending it to: **ME Research UK, The Gateway, North Methven Street, Perth, PH1 5PP**

☐

Please tick this box to indicate you are happy for us to collect and store your personal information, in accordance with our Privacy Policy at meresearch.org.uk.

Name of account holder(s)

Instruction to your Bank or Building Society

To the manager, Please arrange to debit my/our account with the amount detailed below, once every month until further notice.

Account number

Branch sort code

Address and postcode

Debit amount (£)

Payment date each month

Telephone number

Date of first payment

Name of Bank or Building Society

Pay to: Clydesdale Bank, 158/162 High St, Perth, PH1 5PQ, UK, Account: ME Research UK, a/c no: 50419466, Branch code: 82-67-09

Branch address and postcode

☐ **Tick** if you would like us to treat this, any future donations to ME Research UK (SC036942), and all payments in the previous 4 years, as Gift Aid donations, meaning your donation can increase in value by a quarter at no extra cost to you. You confirm that you are a UK taxpayer and understand that if you pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all your donations in that tax year it is your responsibility to pay any difference. Please notify us if you wish to cancel this declaration, change your name or home address, or no longer pay sufficient tax on your income and/or capital gains. If you pay Income Tax at the higher or additional rate and want to receive the additional tax relief due to you, you must include all your Gift Aid donations on your Self-Assessment tax return or ask HM Revenue and Customs to adjust your tax code.

Signature

Date

