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Invest in ME Research

April 2024 Newsletter

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House of Commons Debate - Again!

As we publish this we learn of yet another 'debate' on ME in the UK parliament.

One wonders what is really behind this?

Have we not already covered this in 2018 and 2019 - with absolutely nothing being done?

Why is there a debate before the planned publication of the DHSC initiative set up by Sajid Javid two years ago?

liMER made extensive comment for the previous debates. Nothing changed!

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EMEA Pan-European Survey

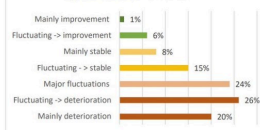
The recent European ME Alliance Pan-European ME Patient survey included a summary of key messages from the survey (available also in multiple languages). Click on the image to the left.

[Subscribe](#)[Past Issues](#)[Translate](#) ▼**Same disease, different approaches and experiences****The report and survey**

This infobrief summarizes the findings from a 2021 survey of more than 11 000 patients with myalgic encephalomyelitis (ME), also referred to as ME/CFS or CFS/ME in some countries. It is the first pan-European patient survey, and compares experiences across countries regarding disease characteristics, course of illness, and access to healthcare and support. The survey was translated into 15 languages and promoted via patient organizations. The questionnaire covered illness characteristics, factors affecting disease course, therapies, and support received from healthcare and other public services, and family and friends.

ME/CFS is a serious and debilitating disease

ME/CFS is typically categorised into four degrees of severity: mild, moderate, severe, very severe. The use of the term "mild" ME/CFS is an oxymoron, as even "mild" ME/CFS is a severe disease, with a major loss of function compared to before disease onset. Most patients cannot work and rely heavily on support. 3.7% had better than mild ME/CFS, 24% had mild ME/CFS, 54% had moderate ME/CFS (mostly housebound), 16% had severe ME/CFS (mostly bedbound), while 2.4% had very severe ME/CFS (bedbound and in need of continuous care). Across countries, we found strong similarities for the distribution of degrees of severity, the positive correlation between early onset and disease severity, and the factors associated with a better course of illness, such as pacing and support from family and friends.

Almost half of survey respondents report a**Typical courses of illness****Early diagnostics and disease management are critical for a more favorable prognosis**

Long delays in the diagnosis were common, with the diagnostic period (from onset to diagnosis) averaging 6.8 years across Europe with large variations across countries. Men are, on average, diagnosed one year earlier than women. Longer delays were associated with a worse course of illness. The risk of experiencing deterioration is more than 50% higher among those with a late diagnosis (10 years or more) compared with those who received an early diagnosis (within 3 years).

The survey confirms what several studies (with smaller samples) have found: delayed diagnosis is a risk factor for severe disease. Early and sound advice on the management of the disease, including pacing to avoid Post-Exertional Malaise (PEM), improves the prognosis.

The health care system fails ME/CFS patients – and that has serious consequences

An easy to read information sheet was also created and is available on the EMEA web site

[Read more](#)

International ME Conference Week Brochure



For our International ME Conference Week 2024 - arranged for 25 - 28 June 2024 - we made a handy brochure highlighting the conference week events this year is available. Something able to be passed on to clinicians interested in learning more about ME.

[Read more](#)

#IIMEC16 Conference



This year, for the public conference on 28 June, we are hoping to have more content that will be useful for clinicians and patients.

Apart from research news, we will have updates from the NIH regarding the recent Roadmap results and of the NIH intramural study.

We will be looking at treatments and how patients are treated in USA and Europe.

Registration is open for the 16th Invest in ME Research International ME Conference - An Update on Research into ME - Advancing ME

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A Favourite Conference Quote

“The whole idea that you can take a disease like this (ME) and exercise your way to health is foolishness. It is insane...”

Dr. Paul Cheney, USA

Invest in ME Research Conference [#IIMEC5 \(2010\)](#)



Dr Paul Cheney made this famous quote as far back as 2010 at our 5th International ME Conference in London [#IIMEC5](#).

#BRMEC13 Colloquium



A reminder to researchers from recognised research and academic institutes of the two-day closed researchers' colloquium at the Wellcome Genome Campus between London and Cambridge, on 26 - 27 June 2024.

The theme - **The Infectious Aetiology of Myalgic Encephalomyelitis**

The event focuses on uncovering the complexities of ME, exploring acute infection, chronic infection, and co-infection.

#BRMEC13 will cover various aspects of ME research, facilitating in-depth discussions on Chronic Infection, Nervous System and Neuroinflammation, Immune System,

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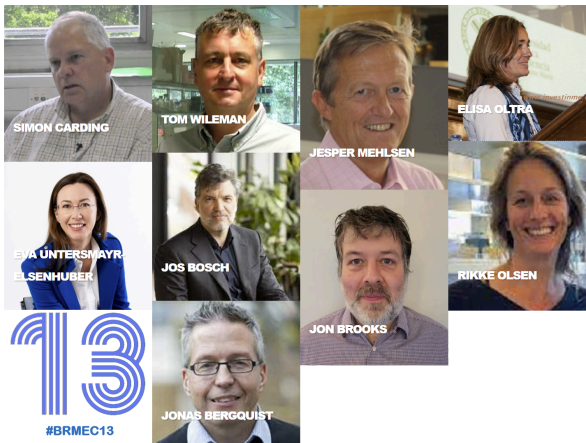
Physiology, and Other Non-infectious Trauma, led by experts from the European ME Research Group.



We are pleased to announce that the National Institutes of Health will be represented at International ME Conference Week 2024 with Drs, Whittemore, Nath and Wallitt participating. Following the completion of the National Institutes of Health Roadmap for ME, and combined with the following IIMEC16 Clinicians' Conference, we seek to focus on answering the pivotal question, "What's Next?" for ME research.

[Read more](#)

#BRMEC13 Moderators



The moderators of the sessions in our 13th Biomedical Research into ME Colloquium in June are described here. We have countries across Europe represented from the European ME Research Group.

[Read more](#)

Young EMERG Workshop

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Are you an *early career researcher* working on ME/CFS or related illnesses?

Join us for our SPARK ME workshop

25th June 2024

Hinxton Hall, Wellcome Genome Campus, Cambridge, UK

A full day cross-disciplinary symposium for current master students, PhDs, postdocs, and medical students researching or interested in ME/CFS or related illnesses.

Expands the multi-disciplinary network to assist and encourage researchers in the field of ME/CFS biomedical research

Opportunity for developing collaborative biomedical research projects

Discussions of research grant opportunities for ME/CFS early career researchers



Register/ Submit Abstracts Online
europeanmeresearch.org/yemerg04.shtml
Abstracts: 16th of April, 11:59pm CET.
Registration: 5th of May, 11:59pm CET.



25th June has delegates from at least ten countries participating. We are also glad to announce that the European Research Council (ERC) is again presenting - this time on specially selected topics chosen by the Young EMERG committee. Young EMERG is an initiative of Invest in ME Research and the European ME Research Group to boost capacity and interest in research into ME in Europe (and beyond).

[Read more](#)

Mike Harley - EU Marathons for ME



Mike Harley has raised enormous awareness and valuable funds for research at the centre of excellence for ME in Norwich Research Park over the last years - running 27 EU marathons, then continuing this amazing venture with additional marathons.



Almost 9000 miles later Mike visits Serbia this weekend to run in the Belgrade marathon. Mike always takes the opportunity to describe how ME is treated in each country that he visits - here Milan and Diana offer views of life

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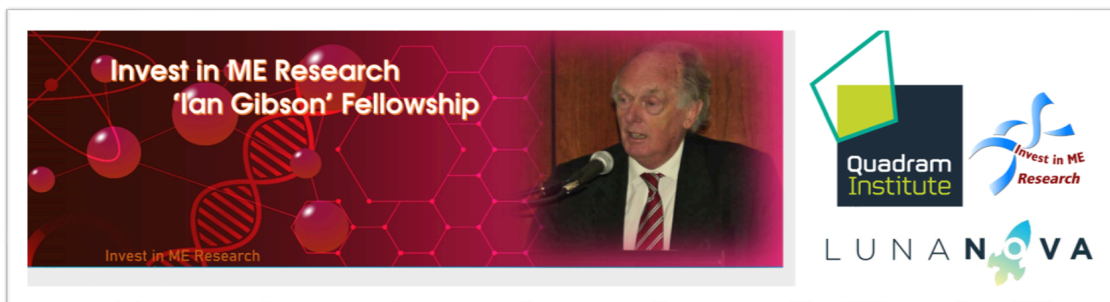
<http://www.mikeseumarathons.eu/serbia.html>

For this marathon Mike has even been on Serbian TV - more good coverage of ME in Europe.

Mike's efforts have raised almost £50,000. Mike's JustGiving page is here -

<https://www.justgiving.com/fundraising/mikeseumarathons>

Research at the Centre



The two new fellowships funded by Invest in ME Research (with the wonderful donation of LunaNova) are also beginning - [more details on the Quadram site](#).



The **RESTORE-ME** clinical trial begins this year at the Quadram Institute in Norwich Research Park. Funded by Invest in ME Research (with a wonderful donation and support from The Hendrie Foundation) this clinical trial offers hope to understand ME and possibly offer a therapy for a subset of patients. At the same time, the charity is working with Quadram Institute to bring in other research to

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collaboration across Europe.

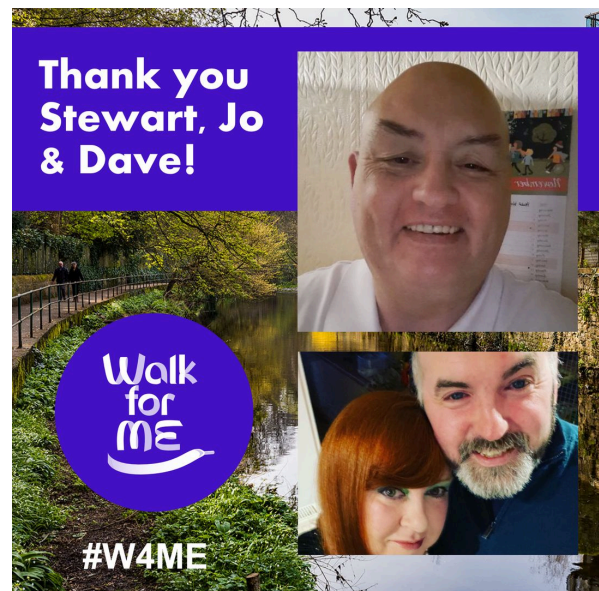
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The **RED LIGHT** study will also be starting soon, having cleared ethics and other necessary regulatory and procedural work. This is among the ongoing and developing research being undertaken and planned at the centre in Norwich Research Park. Professor Simon Carding presented an update on research at the centre, including this red light study, at last year's #BRMEC12 colloquium and #IIMEC15 conference that were organised by the charity.

More about this will be documented on the IIMER web site soon.

[Read more](#)

Welcome back to Walk for ME #W4ME to the amazing Ian Thomson. This is the 4th walk Ian is doing in memory of his late fiancée Sarah Turner who had ME.



Huge thanks ❤️ to Stewart, Jo & Dave who are again Walking for ME along the North Edinburgh ex-railway paths and the Water of Leith Walkway.

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Route raising funds for
Invest in ME Research

Please donate if you are able.
<https://justgiving.com/page/stewart-syme-04052012>

<https://justgiving.com/page/ian-thomson-1712962250782>

Please donate if you can ❤️

Michael O'Reilly



We leave the saddest news to last.

We received news this week of the passing of our good friend and valued and respected advocate for people with MW - **Michael O'Reilly**.

Michael was founder of the Irish ME Trust (IMET). Along with Declan Carroll, IMET were one of the founder members of the European ME Alliance (EMEA).

Michael regularly came to the Invest in ME Research international Conferences in London. IMET has supported every single Invest in ME Research International ME Conference Week - including this year's events.

Michael was just a really wonderful person and a great storyteller.



IMET issued this statement-

It is with deep sadness that we announce the passing of our founding member and chairman Michael O'Reilly.

As well as being a great family man, Michael devoted a great part of his life in helping those with ME in whatever way he could. Due to his foresight and desire to help, our ME Therapy Week was founded in 2003 and took place each year at An Grianán in County Louth until 2016.

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turns to this day, currently in Adare, CC EIMCOK.
Michael was due to attend this year's event which
takes place next month.

He will be greatly missed.

Funeral details at <https://rip.ie/death-notice/michael-oreilly-dublin-blanchardstown-553802>

Ar dheis Dé go raibh a anam dílis

Irish ME Trust



Invest in ME Research is a charity of volunteers - but working continuously to improve the research, treatment and perception of myalgic encephalomyelitis (ME). We welcome support to continue our efforts to advance research and European and international collaboration into this disease.



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