



NEWSLETTER

Welcome to the Invest in ME Newsletter for August 2007.

After our international conference in May we have been working on the DVD of the conference and on other possible projects.

We would like to congratulate ME Research UK on also holding their conference in Edinburgh and in joining with us to mark ME Awareness Month 2007 with two powerful events which we hope will progress the move toward ME being better understood by the public, the media and, especially, by healthcare professionals.

The conferences emphasised how much good research had been performed, was underway and was ready to be performed, provided funding was available to make use of the new technology. The research has moved on considerably in the past five years and we need to make ME a mainstream illness to attract new researchers.

The challenge now is to harness the momentum from the conferences and put it to good use. We are glad to see some collaborative opportunities arising from the meetings which took place at the conference and hope that these will develop into real action to benefit and progress the perception and treatment of ME.

The replacement of the Secretary for State for Health in the UK may provide an opportunity for change. Invest in ME has written to the new minister asking for a meeting to discuss ME.

One feeling we all have is that anything is possible and we have to take whatever possibilities we have to force through change.

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Thank You

Firstly we'd like to say thanks to everyone for all of the letters/emails of support and the donations made to us in the last few months. As with any voluntary organisation these mean a great deal to us.

Also thanks to Wendy P. in Surrey and Frances O'Brien in Naas, Ireland who between them raised nearly £650 during their ME Awareness Month Have a Cuppa for ME days in May. Sales of blue ribbons by the Irish ME/CFS Support Group raised over £6000.

Also worth mentioning is that Robert Saunders is donating all royalties to biomedical research into ME from a book he is publishing. Although the official publication date is not until 2 November 2007, it is available on at [this address](#).



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Statistics on IB and DLA

One of Dr. Vance Spence's comments at the IIME London conference related to numbers of pwme and how this could be extrapolated from the figures on those claiming Incapacity Benefit and Disabled Living Allowance. Janice and Bill Kent promised to research this and they have provided details - [see here](#).

NICE Health Select Committee Investigation

Invest in ME submitted our evidence in the investigation of NICE by the Health Select Committee in March. The submitted article is [available here](#).

Norway - the Breakthrough

IIME were happy to highlight the amazing work of the Norwegian ME Association in getting the government to agree to fund biomedical research into ME and set up competence centres to provide proper treatment.



The focus is still on Norway as it has been announced that the Norwegian ME Association will host the next board meeting of the International Association for CFS/ME (IACFS) in Oslo in October. As the IACFS members will be in Oslo for this meeting they have also agreed to give a conference for patients and for professionals. The objectives of IACFS are to progress, stimulate and coordinate development of ideas related to research into ME/CFS and it is perhaps a sign of the importance of the work by the Norwegian ME Association that this being held in Norway.

Plans for the conference are still being developed and we hope to provide more detail later. Registration for Norwegian ME Association members and relatives will begin at 12.00 Thursday 18 October and that conference day ends at 17.00. The conference for healthcare staff and professional groups working with ME groups will be on Friday 19th October from 08.00 - 16.00.

Details for registration are [here](#).

and the Dominoes begin to move...

As predicted by Invest in ME the breakthrough in Norway is beginning to have its effects. In neighbouring Sweden a similar "interpellation" (a method used to get the government to justify their policy on a particular issue) has been instigated to press the Swedish government on its policy on ME.



In the Swedish parliament (Sveriges Riksdag) a debate was held regarding the situation of patients with ME and the security of their rights within the healthcare system.



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Göran Hägglund answered the ME-interpellation that they had set up a investigation concerning ME on 15 March 2007. He said that SBU (an authority that critically examines methods used in healthcare to diagnose and treat illnesses - similar to what the UK NICE should be?) had been given the task to research the literature in order to give advice on which diagnostic criteria should be used and which treatment is recommended. We hope to report news of this at a later date.

The International ME/CFS Conference DVD



The International ME/CFS Conference 2007 is now being produced for delivery. Our apologies for the delay. We hope this will be another aid for educating people about ME. The price is £15 for UK delivery, £16 for European delivery and £17 for USA, Canada and Australia.

To order the 2007 Conference DVD click [here](#).

The 2006 Conference DVD is also still available as an excellent educational aid.

Use the conference links below to keep up to date with the latest information on the conference.

[Conference Review Home](#)

[Conference Feedback](#)

[Order DVD](#)

[Awareness Month](#)

[Conference 2006](#)

Petitions

On the conference DVD one can listen to Dr. Sarah Myhill describe her treatment programme for people with ME. Dr. Myhill is having to defend herself to the General Medical Council, despite no complaints from any patients.

The Sunderland and South Tyneside ME/CFS Support Group have set up a petition of support for Dr. Myhill and this is still open for new signatories until the end of August. If you wish to add your support for Dr. Myhill please click [here](#).

ME Stories

"I haven't seen a doctor in years. It doesn't seem worth it, somehow, as they have no answers and, besides, I can't stay upright long enough to make it to the surgery. I become light headed very quickly now and have to lie down before I fall down: something else that used to happen on exertion and which now happens all the time."



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Thanks to Christine for submitting this. Read more of Christine's story [here](#).

Read other ME stories [here](#).

The Journal of IiME

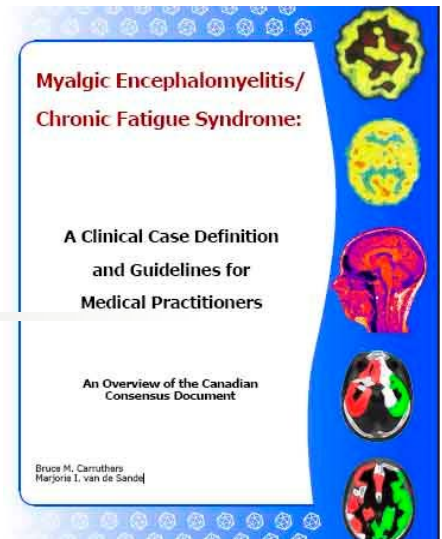
We hope to publish our second issue of the Journal of IiME in September. Thanks to everyone for the comments returned regarding the first issue. The Journal Issue 1 is currently [available here](#).

...and the Quotable Quotes Booklet

is still available. Compiled by Margaret Williams the ***QUOTABLE QUOTES ABOUT ME/CFS*** booklet costs £3.50 plus postage and packaging and is available [here](#). This is an excellent source of information to provide to your MP, GP or paediatrician.

Canadian Guidelines

Invest in ME have been given the rights to distribute the Canadian Consensus Guidelines in the UK. We have already made an order for an initial batch. If you or your group would like to order copies please email us at [this address](#).



ME Clinics

At the London conference there was animated discussion on the role and usefulness of the CNCC clinics. IiME's position on these clinics is that, if they provide nothing but psychiatric paradigms posing as treatments for a neurological illness then they ought to be closed and the money transferred to biomedical research. Having a psychiatrist as chair of the CNCC can only cast more doubt on the role and strategy behind them.

But if these are not the clinics that are required then what is it we need from them?

As part of a move to establish basic protocols for ME we have added a document to the web site produced by Linda and Greg Crowhurst who have made a start on defining what we need and what we don't need from ME Clinics. We publish their document - [click here](#) - as a starting point for a consensus on what should be provided by clinics funded by the government and whose purpose is to treat ME patients.

Any comments you have to expand, refine or supplement this will be welcome. Send your comments to [this address](#).



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Support ME Awareness - <http://www.investinme.org/>

