



Invest in ME Research

NEWSLETTER



November 2008 Newsletter

INSIDE THIS ISSUE

International ME/CFS Conference 2009 - London, UK

Lost Voices

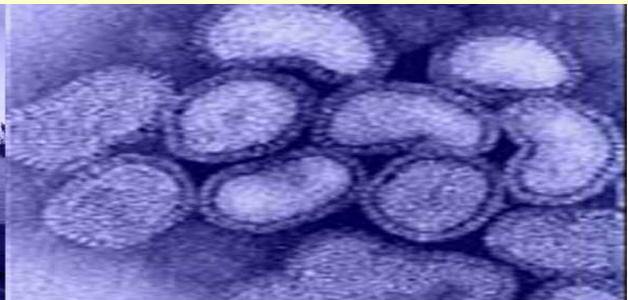
The European ME Alliance

Recent ME Events

Journal of IiME Vol 2 Issue 2

Welcome to the November 2008 newsletter.

International ME/CFS Conference 2009 - London, UK



The 4th Invest in ME International ME/CFS Conference 2009 will be held on 29th May 2009, in London.

In this conference we will be trying to focus more attention on those severely affected by ME.

More details will be coming out in mailshots and newsletters leading up to and past Christmas.

Invest in ME Newsletter November 2008

We shall again be offering our **Sponsor a GP** scheme which allows a discount rate for healthcare staff who are affiliated/recommended by a local ME support group or organisation.

Once again we would ask all ME/CFS support groups/organisations to make their members aware of the conference and to try to get as many local healthcare staff as possible to come along. If people are too ill to attend then please try to get relatives, friends or carers to come along and learn more about diagnosis, management, treatments and research into ME/CFS. Discounted rates will be given to people with ME and their carers.

Support groups and friends of IiME can help us by taking our flyers/posters to local GPs/consultants or placing them in hospital waiting rooms so that more people can become aware of the conference. IiME will send out flyers/posters or other details to any groups who wish to include them with newsletters to members. Contact us if you would like us to send you anything. The conference web pages will be available shortly.

Last year's conference had representatives of twelve different countries present making it a truly international event. Please support us in our efforts to promote awareness of ME and show up to date information on diagnosis, management, treatment and research into ME/CFS.



LOST VOICES

Invest in ME's Book Project - '**Lost Voices**' - is now about to be printed and we are offering a discounted rate for those pre-orders placed before the end of the year.

If there is one book on ME that you buy then make it **Lost Voices**. The book has been ongoing since our conference last May and Natalie, whose idea this was and who has devoted most of her waking hours to this project since our last London conference, has performed a quite amazing job.

The book is of extremely high quality and is offered by Invest in ME at a reasonable price to allow more people to be able to purchase it.

Invest in ME have been aided in the funding of the production of this book with some wonderful donations - one from a private source and one from Malvern College - who have made Invest in ME one of their charities of the year and we also wish to thank the 25% Group for their kind donation toward the production of the book.

The early-purchase discount rate has been set at £8.00 (£9.00 for European delivery and £11.00 for delivery elsewhere) and will include postage and packaging. This applies to all payments received before 1st January 2009. After that date the price will be £13 for delivery outside Europe. Please contact us or look at the web site for more details.

The book is an A4 landscape size with a laminated card cover with pictures, mostly in colour. With around 120 pages of stories, pictures and information this is without doubt the only book around which truly encapsulates the tragedy of this illness and the way in which people with ME are left to exist in a twilight zone - left to deal with this illness by themselves and with no hope of a future. The moving stories convey the real picture of ME.

And yet Lost Voices will show the resilient character of people with ME and their families.

The book also contains facts about ME with contributions from experts such as Dr. John Chia, Dr Leonard Jason, Dr Vance Spence and others.

Please buy this book - for yourself or for friends, relatives or your GP - or suggest it as a gift for others to buy.

This book will really make a difference.

More details can be found by [clicking here](#).

The European ME Alliance



As most may have seen from the recent press release the European ME Alliance has been formed to promote awareness of the need for biomedical research into ME/CFS. The founder members of the Alliance are from Belgium, Denmark, Germany, Ireland, Norway, Sweden and UK and contain many very experienced advocates for the cause of ME. We hope soon to have more countries in Europe represented in EMEA - thus creating a broader European voice.

EMEA will be setting itself up over the coming months and one can expect to see further developments. Use the web site at

<http://www.europeanmealliance.org/www.europeanmealliance.org> or, for short, <http://www.euro-me.org/www.euro-me.org>.

The 4th Invest in ME International ME/CFS Conference is supported by EMEA and will be our first in which we'll be working with the European ME Alliance. Members of EMEA will be at the conference and will be holding the first EMEA AGM at the same time.

Recent ME Events

Comments recently made by the Countess of Mar regarding CBT/GET and NICE have been made public - in which she states her qualified support for CBT/GET and for the NICE guidelines.

IiME maintain our opposition to the NICE guidelines as being unfit for people with ME and we believe it is unacceptable to compromise. Adding caveats that they may help some if the therapists are properly trained in ME carries little value as almost everyone practising CBT/GET for ME patients has been trained to treat ME as a behavioural illness.

The promotion of CBT or GET as first line treatments for a neurological illness such as ME is also profoundly irresponsible and deceitful.

IiME feel the Countess has been a welcome proponent of the need for biomedical research into ME and we cannot understand this change in attitude, at this particular time. We cannot agree with her stated position of supporting the NICE guidelines and any recommendation of CBT/GET as a serious form of treatment for a neurological illness.

The MRC rejected the offer which IiME facilitated from the Whittemore-Peterson Institute to visit the WPI centre in Nevada. Yet it was recently announced that the MRC was to meet with two ME charities in December to be informed of their plans for producing a multi-disciplined approach to ME. We would hope that the MRC would be talking seriously to biomedical researchers. That was the aim of IiME's attempts to engage the MRC staff dealing with ME/CFS (by providing free places to our international conferences so that they could hear the latest biomedical research on ME, by offering them space at our conferences to speak on their policy regarding ME and by including articles from the MRC on their policy toward ME in our conference Journals).

Our view regarding any initiatives by the MRC to include researchers who view ME as a functional somatic syndrome in a future "multi-disciplined" research strategy were commented on in our June newsletter ([see here](#)) and nothing we have heard since changes our view.

Expect to see the psychosocial view of ME being joined to a biomedical view - for appearances sake.

At the time when we launch the Lost Voices book - showing the tragedy being caused by the MRC's lack of appropriate action - we are doubtful of the MRC intentions and of the need to speak to pre-selected ME charities to gain some support for their policy. We have yet to see the MRC seriously consider funding of biomedical research into ME - the only route to providing any serious breakthrough in treating the illness.

The rushed and under-developed Terms of Reference for an inquiry into NHS services by the Parliamentary APPG group for ME was commented on by IiME [[see here](#)].

All of the above are isolated, non-related incidents. Or are they?

We see how much time and energy is being devoted by people with ME and their families to dealing with these issues - either in giving false hope that some valid change is coming; or in having to respond to an incomprehensible change of opinion from an erstwhile campaigner for the rights of people with ME; or to have to challenge and complain about the lack of adequate planning or strategy being given to ME by the APPG.

We hope these events aren't attempts to distract us from the one event which we should all be concentrating on at this point in time - the unacceptable NICE guidelines.

Our attention should be focused on NICE's day in court when they are brought to a Judicial Review.

Journal of IiME Vol 2 Issue 2

Our Journal of IiME is just awaiting one last article before it is distributed. Watch out for the mailshot soon,

Best wishes to all

Invest in ME

[Go to Newsletter Home Page](#)

Invest in ME - Research

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