



# Invest in ME Research

# NEWSLETTER



## May 2007 Newsletter

Welcome to the Invest in ME Newsletter for May 2007  
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## ME Awareness Month - May 2007

This is the second ME Awareness Month which Invest in ME has participated in as a charity and, if the spirit of the International ME/CFS Conference which was just held in London, is anything to go by then we should have an eventful month ahead.

With the first of the month's ME/CFS conferences already behind us we look forward to the other events in May which will raise awareness.

A reminder that our flyer for ME Awareness Month is available from the ME Awareness Month page - the theme - [Energising ME Awareness](#).

We have again asked Google to honour people with ME by making a **Google-Doodle** - [see here](#). Let's see if the biggest search engine around can find it in its collective heart to spare some time for those who seem not to be visible to many people deciding research funding and healthcare policies.

We wish everyone organising or participating in any awareness event the best of luck.

This month

Best wishes,

All at liME

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## Short takes

### Gibson Inquiry

Dr. Ian Gibson's Inquiry group is scheduled to meet to discuss revisions to parts of his report. This was announced at the International ME/CFS Conference in London.

### Norway - the Breakthrough

The applause which was given to the Norwegian ME Association at the International ME/CFS Conference in London is hopefully a sign of the significance and recognition of the news from Norway on the initiatives being taken there ([see here](#)). liME are attempting to get Minister Sylvia Brustad and Dr. Ian Gibson to meet and re-inforce all of the positive recommendations from both initiatives.

### Visit to MRC

liME will be meeting up with the MRC soon to discuss issues relating to ME and biomedical research. This follows on from contacts made prior to the International ME/CFS Conference.

### Research Proposal

The research proposal to provide two UK centres for full body analysis of people with ME, with Dr. Byron Hyde and Professor Malcolm Hooper, is continuing. We shall provide more details when we can although this is obviously not a project which will be completed without a good deal of preparatory work.

## Raising ME Awareness in Spain

Clara Valverde has provided us with additional information from Spain, in the form of a powerpoint display. We show it here.

Clara reports from Catalonia where, until a few years ago, the illness wasn't even recognised. The problems encountered by Clara are similar to those in other countries and it, again, is only because of ME patients that any publicity is generated for the illness.



An illuminating slideshow from a dedicated and determined group of campaigners.

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## The Journal of liME

Hopefully many will have noticed the first Journal of liME on the web site. Our hope is to supplement the newsletter with this publication as often as we can - but at least four times a year. The publication will be free from our web site. We also hope to raise funds to print it and distribute it to healthcare staff.

Our thanks go to our contributors who helped augment the conference pack for delegates at the International ME/CFS Conference. New to the version of the Journal on our web site is the article from Professor Colin Blakemore of the MRC which came too late to be included in the conference version.

The Journal is currently [available here](#).

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## and the Quotable Quotes Booklet

still available - the QUOTABLE QUOTES ABOUT ME/CFS booklet. Compiled by Margaret Williams it costs £3.50 plus postage and packaging and is [available here](#). This is a limited run so please order now.

An ideal present for anyone needing to perform research, compose letters or verify facts.

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## International ME/CFS Conference Review



Another International ME/CFS conference is over. The 2nd International ME/CFS Conference 2007 was completed at the beginning of the month. Delegates and presenters from USA, Canada, Europe

and South Korea attended and created a special atmosphere which is a credit to people with ME, their carers/parents and those researching/treating the illness.

Our conference review pages are now available with a gallery already present from Regina Clos, from Germany - [see here](#).

We feel that good and useful connections have been made - researchers discussing collaboration; ME Support groups discussing joint ventures and campaigns; carers and parents sharing experiences. The conference, held over two days, was another special event.

Thank you to those ME Support groups who facilitated the attendance of local GPS and healthcare support staff at the conference. We hope these links will continue at a local level and would be keen to hear from anyone of any results experienced from the conference.

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## Conference DVD

Invest in ME are producing a DVD of the International ME/CFS Conference and we hope to make it available in early June 2007. The DVD should have all of the presentations from both days of the conference.

We also have a surprise in store with special interviews with several of the presenters.

The interviews were conducted by Professor Malcolm Hooper who, besides a full day of discussions and presentations, also managed to use his vast knowledge of the subject area to quizz selected speakers.

We'll leave the rest as a surprise for now.

<http://investinme.org/IIMEC2.shtml#dvd>

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## Anecdotes from the Conference

Thanks to Susan for reminding us of Professor Malcolm Hooper's riposte to those who believe ME is all in the mind - "**Offer them a blood transfusion**". It was, indeed, brilliant.

Thanks to Rebecca who gave us this encounter from the conference -

"How can any doctor look at the facts and doubt it is a physical disease. And yet...there was a least one doctor there who still was a Wessley-schooler. On the second day, I sat next to this man and when I told him I had ME/CFS he told me to try deep breathing techniques and asked me if I was a person who had a lot of self-doubt..... so...you can lead a fool to facts, but you can't make them think!"

which takes us in nicely to the next story.....

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## and finally a Horse Story

Something, perhaps, not directly related to ME but perhaps interesting for those interested in associations between chronic illnesses - although this article refers to horses. Bill O'Gorman has provided this article concerning Lyme Disease and the performance of race horses - [see here](#).

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