



Invest in ME

NEWSLETTER



June 2006 Newsletter

Newsletter June 2006

INVEST in ME

No.06/04 / June 2006

NEWSLETTER

Welcome to the **Invest in ME Newsletter** for June 2006.

This newsletter follows the ME Conference in London on 12th May.

The conference emphasised how much research had gone on, was going on and was ready to be performed, provided funding was available.

The challenge now is to harness the momentum from the conference and put it to good use.

There are several new ideas arising from the conference which we hope to make into real action which we feel will produce benefits and progress for the perception and treatment of 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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Conference Review



The ME Conference 2006 brought together delegates from 6 countries and forged new relationships between people who are determined to safeguard proper funding for treatment/cure for myalgic encephalomyelitis. Looking back it was a wonderful day with a wonderful atmosphere. The positive and friendly attitude of everyone removed the myth of people with ME being depressed or anxious. People wanted to listen and learn and hear from experts.

IiME worked hard to attempt to get as much publicity for ME as possible - working right up to the day before the conference. Media articles referencing the conference and/or the work of presenters at the conference appeared in The Daily Mail and the New Scientist. BBC Radio Five Live interviewed IiME in ME Awareness Week with a phone-in and ITV Meridian covered the conference and had two consecutive evenings where stories were shown - one of which made the national ITN network.

We also finally got, at the 11th-hour, a representative from the Medical Research Council and she bravely joined in the discussion forum at the end of the conference - something which can be seen on the conference film.

For more feedback and pictures from the conference look at our feedback page [here](#).



For those delegates who were at the conference please share your experiences, if you haven't already done so, and let us know what you thought and what you are doing now. Contact IiME [here](#).

Order the Conference Film

Invest in ME have set the price of the conference film at £13 plus postage and packaging for UK delivery - so a single dvd set delivered in the UK will cost £15. There is a discount for bulk orders. The DVD should be available at the beginning of June and will contain all of the conference presentations in full. We also hope to include additional information on the DVD.



To register or for more details [click here](#). We are also working on an idea to produce a mini-DVD for distribution to GPs and MPs. More details will be coming soon. If we break even on production of the DVD(s) we hope to make a donation from any profits to one or more of the biomedical research charities (e.g. MERGE/CFSRF).

The Gibson Inquiry



IiME were happy to facilitate the participation of two of the presenters at the ME Conference. Ian Gibson's office requested IiME to contact both Bruce Carruthers and Byron Hyde to see if they could attend the Parliamentary Group on Scientific Research into ME's meeting on 10th May. It was a great gesture by both doctors to attend at such short notice. Byron Hyde had literally travelled straight from the airport to the inquiry after arriving from Canada. How important that was as they were facing people from NICE.

ME Stories - 1

Another story to add to the ranks filling our pages -

"My GP thought I had ME but kept saying, work through it, do lots of exercise you'll get over it. They sent me to a sports centre to do a fitness course but I went once and never again. It was about this time I saw the psych and he said there was nothing mentally wrong that feeling well again wouldn't fix."

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

ME Stories - 2

and another...

"When I try to get medical care, the strain of trying to convince someone I am ill and the hurtful things they say to me practically make me crack up. Just the physical demands of leaving the house, even in the wheelchair, are enough to make me sicker for weeks. I can't describe how ill it makes me."

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

Read other ME stories [here](#).



ME Stories - 3

Nobody at the ME Conference could have failed to be moved by the words of Criona Wilson who told the harrowing story of her daughter Sophia - perhaps the first recorded death from ME in the UK. Criona was also interviewed by ITV Meridian in the days before the conference and this programme has been added to our site with the permission of ITV - [see here](#). We also have the story of Sophia and M.E. - [see here](#).



This is the UK in 2005-2006 - and should be compulsory viewing for all charities, organisations and healthcare staff involved in M.E.

Other ME Groups/Contacts

We have updated our Web Links page with additional contacts and regrouped into new categories - [see here](#). Also this month a quick view from Denmark and Lajla Mark in our Guest Groups/Contacts section - [see here](#).

If you would like to be included in our Guest groups please [email us here](#).

Byron's Little Red Book(let)

Dr. Byron Hyde produced a little red booklet for the ME Conference. He took the trouble of making 280 copies of this - and they all went.

Dr. Hyde has given IiME permission to use this booklet and it will be available [here](#) as soon as we have verified some outstanding issues.

Dr. Hyde will be refining this booklet and latest copies can always be found at his Nightingale Foundation in Canada - see www.nightingale.ca

IiME Campaign

As indicated at the ME Conference by Jane Colby M.E. is no longer a notifiable illness at schools. Why not? IiME wish to support the call for this to be changed and we are writing to the CMO and Dr. Ian Gibson to raise support for this. We shall show the status next month.

Thank You

...for the donations - we would name those who have donated but some prefer to remain anonymous....but we want you to know that it is really appreciated. IiME is made up of pwme or carers/parents of pwme and nobody receives any salary or 'running' expenses. So these kind gestures do really help. Thank you again.



and finally.....

IiME have made a decision to repeat the ME Conference for May 2007. Venue and dates to be announced. We hope to make it an even better conference in 2007. More details will be coming soon.

Contacts:

Inquiries to Invest in ME - info@investinme.org

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