Invest in ME
NEWSLETTER

# Welcome to Our January Newsletter

Invest in ME
Research

Greetings from IiME

Welcome to a short January 2009 IiME Newsletter.

INSIDE THIS ISSUE

## Lost Voices

The Lost Voices book is now being distributed. Written by people with severe ME, their carers, some children and filled with pictures from families affected by this illness, and contributions from experts on ME this book should change perceptions on ME.

Some comments so far from people purchasing the book –

> "The book is stunning.
>
> The contributors must be delighted to see their personal stories presented in such a sensitive & respectful manner."
>
> "Am quite overwhelmed. It is amazing!"
>
> "The book is so moving. thank you so much for publishing the book"

For those purchasing the book please add to our comments section - see here.

The Lost Voices home page is here click here.

Invest in ME have sent the book to a number of (hopefully) influential people whom we hope will be moved to help us gain proper recognition for this illness. We are also applying for grants to enable each MP and more GPs to be able to receive this book. We also hope for every library to have a copy.

We have to thank Natalie for all of the work she has put into this to create such a unique and powerful product, and thanks also to Iain and Josh and Oliver and, of course, Anna for their support and contributions. Without Graham's contribution and that of Sandy and Malvern College it would have been more difficult for IiME to have published this book and we want to thank the 25% Group for their kind donation which also helped us deliver this book. and, of course, we must thank the contributors to the book for having the courage and determination to allow their stories to be shown to the world.

We would welcome all help to publicise Lost Voices. If anyone does send a copy to their MP or GP or PCT please can you inform us so we know which areas are covered.

IiME have paid for an advert in the next edition of Action for ME's magazine in order to publicise the book's message and also the conference. As many people as possible must be made aware of the situation with ME.

We truly believe the book can help change the way ME is perceived in this country and abroad.

## IiME International ME/CFS Conference

Our thanks to ME groups who have taken our conference flyers and distributed them (the flyer is available here). For the benefit of those without printers or for smaller groups we can supply these.

Our scheme for healthcare staff is meant to attract professionals to the conference and allow a connection to be made to a local support group, thus benefiting both in the future. IiME spend a lot of time informing/inviting various departments and professionals to attend and it would help everyone if patients and/or carers could write asking/demanding that these professionals attend. The ***Sponsor a GP*** scheme depends on help from the ME community.

IiME is also self-funding some tickets for medical students (see next story).

A conference update newsletter will be distributed shortly detailing some exciting news regarding the conference as well as the agenda for the conference.

Click here for conference home page

## IiME Biomedical Research Fund

For some while we have been thinking that we need to try to attract more funding which we can direct toward biomedical research - research which can be performed without the constraints or influence of a powerful psychosocial lobby which still influences MRC

Donations which we receive are used to support the international conferences, educational dvd production, production of book and guidelines and postage costs related to these etc.

Education is a major part of biomedical research. Students need to attend conferences such as ours, healthcare professionals need to have the latest research presented to them regarding ME and researchers themselves need to meet, network and establish working relationships with each other. Researchers must also begin sharing data and working in co-operation.

We want to continue to fund education and provide the platform for the biomedical research conferences. We also wish to try to support other areas of biomedical research - by funding biomedical research staff, providing educational opportunities and in assisting with equipment and other costs of researchers performing purely biomedical research into ME.

So IiME is now planning on setting up a fund for these activities. We have no illusions we will be a major force in supplying funding for biomedical research. But we are committed to trying and hope other ME charities will do the same.

To begin this we are allocating 20 tickets to the international conference on 29th May (funded by IiME) to medical or healthcare students in order that they may come and listen to the latest information on management, treatments, diagnosis and the latest advances in research into ME. In the UK medical students receive little education regarding ME and it seems often to be influenced by biased or outdated information. We hope to change this.

## MRC and Biomedical Research

In recent months we have attempted to urge caution on the news of the UK Medical Research Council's plans for a "multi-disciplinary" panel to be set up for ME.

We are concerned that this panel, under Professor Stephen Holgate, is meant to marry the psychosocial view of those who perpetuate the myth of ME being a behavioural disorder with biomedical research. Have the MRC attempted to sweeten the perception of this panel's objectives by including two charities in the panel - in this way supposedly giving it authenticity in the eyes of the ME community?

How would this work if the two quite distinct sets of participants are studying different people and using completely different ME guidelines? What could this achieve but a total fudge and a complete blending of ME with the other nebulous chronic fatigue states so beloved of the psychiatric lobby.

One will likely hear much comment from this panel that the MRC panel is discussing biomedical research into ME.

We believe this scenario now represents a worrying and less than ideal future for ME.

We believe that money will be provided for ME by the MRC - at long last.

However, we also believe that the reason that the MRC panel is made up of many notable psychosocial proponents augurs badly for people with ME and their families.

The MRC have supported and funded the psychosocial view of ME for years and we don't believe their true objectives will change quite so quickly.

The PACE and FINE trials - the two ugly sisters of MRC policy on ME (see here) - are unscientific and essentially worthless trials funded by the MRC at the expense of true biomedical research. They will soon draw to a close and their results are almost certain to appear that CBT and GET are beneficial for people with ME. These studies are a not representative of ME but their results will be used to "justify" MRC intentions to perform more psychosocial research under the guise of biomedical research.

Professor Holgate's stated intention of tying both biomedical and psychosocial factions together will be a liability for future research.

**So picture this scenario** -

- The MRC panel will state that it will promote biomedical research and lull the ME community into a false sense of progress
- The PACE and FINE trials will produce reports stating that CBT/GET are useful for ME patients
- The MRC will announce that it is investing heavily into research in ME
- The psychiatrists who have for so long monopolised the funds will control or heavily influence pseudo-biomedical research which will be aimed at proving that psychiatric paradigms being used for treatment of ME actually show biological evidence of their effectiveness
- The psychiatrists will still control what the MRC fund and how they fund it

We are concerned that the MRC may masquerade their true psychosocial bias by merging biomedical research with input from psychiatrists and will force through findings that CBT and GET really make a difference. Such trials will be able to prove almost anything.

And so people with ME and their families will be consigned to another two or three years of false hopes and, eventually, wasted opportunities.

Another major concern may be that organisations (and biomedical research charities) which do fund and/or perform biomedical research will start to chase this new MRC money at any cost, under the illusion that the "MRC-funded" label will give authenticity to their research - even though it may well be constrained by manipulation from psychiatrists and destined to validate the views of psychiatrists.

Professor Holgate is now in a position where he can be open and honest about the MRC intentions or he can perform a monumental subterfuge with the future of pwme being the casualties.

Professor Holgate has once again been invited to the IiME International ME/CFS Conference.

We hope this year he will accept - there is a lot he needs to think about.

## RESEARCH NEWS

### Diagnostic Test - New Research

One of the key objectives with IiME campaigning was to produce a diagnostic test which could be applied to ME. Our 2008 conference in London publicised the work and need for sub grouping of ME.

Now Dr Sarah Myhill has recently published a paper relating to a ATP testing which could provide the biomarker required for producing and implementing such a test.

Dr Myhill discussed mitochondria in her presentation at the IiME conference in 2007 (available on our 2007 DVD - see here) and this research provides an exciting possibility for the future.

Read more about Dr Myhill's research - click here.

See also Dr David Bell's article about mitochondria - click here.

Mitochondrial disease was covered in the Journal of IiME Vol 1 Issue 2 (click here) with the French researcher Dr Marisol Corral-Debrinski (Gene therapy for mitochondrial dysfunctions using optimized mRNA transport to the mitochondrial surface) - research which posed the question of whether "molecular addressing" could treat mitochondrial diseases?

## Dutch Study on CBT

A recent Dutch study has shown that CBT and GET is ineffective and that patients are unhappy with the way that doctors diagnose ME. See the press release from Dutch ME patient organisations - click here.

## BBC Publicises Bad Research

Recently the BBC web site gave publicity to research by the CDC and published in the journal Archives of General Psychiatry which stated that low levels of the stress hormone cortisol marks out children at a higher risk of developing chronic fatigue syndrome as adults - a deeply flawed study which is neither scientific nor accurate.

IiME followed this up and challenged this article and its inclusion on the BBC website, using comments by Hillary Johnson (author of Osler's Web) [see here].

We objected to this article from the BBC and were invited to submit comments to counter the CDC article - which we did as below –

> Quoting Hillary Johnson, author of *Osler's Web: Inside the Labyrinth of the Chronic Fatigue Syndrome Epidemic*, Invest in ME state that the CDC study had broadened the definition of the disease to include not just those with the actual immune syndrome, but also people who were simply fatigued.
> This study fails to point out findings reported by Taylor and Jason (a study performed in 2001) who found prevalence rates of sexual and physical abuse history among individuals with CFS were no different from other other medical conditions, including medically based conditions.
> Invest in ME believe this CDC Emory study has no relevance to people with ME and should not generate headlines.
> Invest in ME wonder why, out of the dozens of scientific papers published about the actual chronic fatigue syndrome every month in more distinguished journals, it is just this CDC Emory article given publicity?
> To quote Hillary Johnson "This is part of a long-time strategic effort to promote the CDC's longstanding propaganda that M.E. is a personality disorder. It's the latest in a continuum of miguided, money-wasting research by epidemiologists who aren't really qualified to be undertaking basic research into such a complicated and serious disease.".

To quote Hillary Johnson "This is part of a long-time strategic effort to promote the CDC's Though this wasn't given the same space we managed to convince the BBC to add our rejection of the flawed research presented by the CDC - see the latest version of the BBC page here.

Ignorance is widespread and needs to be tackled constantly.

## NICE - Judicial Review - 11-12th February 2009

As the day of reckoning for NICE and the much criticised guidelines for ME draws near we would like to publicise the arrangements made for supporting the actions of Douglas Frazer and Kevin Short, ME patients who have forced a Judicial Review of NICE.

Annette Barclay has set up a web site detailing arrangements for attending the law courts in London to support the JR. The link is here - http://www.nicemecourt.co.uk/index.htmlhttp://www.nicemecourt.co.uk/index.html.

IiME are hoping to get someone to the JR which takes place on **11th and 12th February**.

The Journal of IiME Vol 2 Issue 2 also covered some aspects of NICE and we have taken one of those articles from the Norwegian ME Association and made it available as a web page (click here) - an indication that NICE does not just affect the UK - it has the capability to damage healthcare systems across Europe.

## Sophia

For almost three years now we have carried the story of Sophia Mirza on our web site with a constant link on our home page (see here). Sophia's mother Criona has recently created a You-Tube video which is worthy of looking at [http://uk.youtube.com/watch?v=7mZMpvtD3rghttp://uk.youtube.com/watch?v=7mZMpvtD3rg].

## Journal of IiME

Just a reminder that our Journal of IiME was published in October and, in case people missed it, we have listed the articles in the Journal below.

The objective with the Journal to provide research, information and stories about ME to healthcare staff, media, patients and patient groups - all for free.

The Journal Volume 2 Issue 2 can be downloaded from here - and includes articles from -

- Dr Leonard Jason - "Family Illnesses Among People with ME/CFS"
- Dr Martin Lerner - "Letter from America"
- Dr Bruce Carruthers - "The More Things Change the More Things Stay the Same"
- Wheelchair Use and Attitudes by Sue Pearkes
- S. Pierce and P.W. Pierce - "The Physiology of Exercise Intolerance in Patients with ME and the Utility of Graded Exercise"
- Norwegian MEA - The NICE Guidelines for ME/CFS - Reasons for Rejection
- Nan Socolw - "2 Score and 5 to 3 Score and 10"
- Norwegian MEA - "Reasons Why ME Does Not Belong to the Medically-Unexplained Symptoms category"

## Raising Funds for Biomedical Research

Invest in ME supporter Helen Milstein is raising funds for IiME to support biomedical research (click here)

Helen, whose daughter has ME, has been swimming outside in the unheated water of Tooting Bec Lido twice a week since last October.

If you wish to join her or support her in this please let us know. For further details go to this link - http://tinyurl.com/av85yy*http://tinyurl.com/av85yy

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