Invest in ME

NEWSLETTER

## January 2007

In December 2005 IiME published its first newsletter. A year later, at the time of year where people traditionally look forward to renewal and a positive change in their future, so it is with people with ME - in a year which will be crucial for the future for ME sufferers.

Our topics for the first newsletter of a year ago included - the Gibson Inquiry; the start of the Have a Cuppa for ME fundraising events; news of the first International ME Conference in London; an attempt to create more ME awareness possibilities by replacing a week of campaigning in May with ME Awareness MONTH; the first Meridian ME story being publicised and an article criticising the attempt by some to change the name of ME.

**IN THIS ISSUE**

It seems to be the lie of the land with ME that we are doing similar things a year on. But 2006 was, for us, a year of building foundations. 2007 needs to see some significant progress with regard to ME.

A number of challenges will present themselves this year - the follow-on from the report from the Gibson Inquiry will determine what changes in strategy are implemented by the Medical Research Council following the call to treat ME as seriously as cancer or heart disease. Despite statements in the report with which some take issue it still represents an opportunity for change which needs to be taken. There is no queue of politicians in the wings who are eager to take up our cause.

The attitude of NICE will be on public display when we see how they respond to the overwhelming criticism of the Draft Guidelines for CFS/ME. The planned publication of these guidelines in April without any changes will be fought by most within the ME community. If there is one element which should unite the ME community it is the opposition to these proposed NICE guidelines and the IiME and ME Research UK Conferences in May will allow platforms to publicise everyone's concerns should NICE fail to react.

We feel it is opportune in this issue to review briefly where we are at the start of 2007 - what has happened since the Chief Medical Officer's Working Group report of 2002 or since the Medical Research Council's briefing strategy of 2003. What is the status of biomedical research into ME and, indeed, the status of the ME community?

Despite everything we remain positive that change will come and that ME will eventually get the correct funding, attention and treatment which other mainstream illnesses receive by healthcare services, the media and the public.

**Invest in ME** would like to wish a Happy New year to all our friends.

## ME in 2007

So let us look at the current status of several areas relating to ME.

## UK Department of Health

Anyone who has used our Letter to MP model letter and received an answer from the DoH will be familiar with the apathy shown by successive DoH ministers. By distributing the same template to ME patients (via their MPs) and then referring all responsibility for biomedical research to the Medical Research Council they have shown little interest in tackling this problem or in understanding the true nature of the illness.

Secretary of State Patricia Hewitt has been invited to the ME/CFS Conference in May 2007. This offer has been rejected by her department.

## Status of CMO Working Group

The report to the CMO from the CFS/ME Working Group in 2002 contained the following in its foreword -

> Unsurprisingly, when so little is known about the cause of CFS/ME, there are concerns from patients and their representatives, and from a broad range of clinicians, over the way the illness is managed. These concerns on management apply to the NHS, to other government Departments and to the private sector. In particular, patients and health professionals involved in the care of CFS/ME find much disbelief about the nature of the illness and of its impact. Perhaps as a result, in many areas of the country there appears to be a lack of appropriate health care facilities.

In the four intervening years the amount of progress achieved has been less than desirable. There still exists this "*disbelief*" from the healthcare services which the CMO Working group's recommendations were meant to change. So on to the CMO Working Groups' recommendations. Have they been achieved? In the five areas of the section on recommendations we comment on the status - see here.

Sir Liam Donaldson has been invited to the ME/CFS Conference in May 2007. This offer has twice been rejected.

## Status of Medical Research Council

Since the Medical Research Council's CFS/ME Research Advisory Group from 2003 was commissioned and followed on from the CMO's Working Group of 2002.

We examine the status since this report was issued (see here) and again find that another government health institution has patently failed to deliver on its publicly stated intentions.

Seven years ago one had these stories in the BBC Panorama programme -

http://news.bbc.co.uk/1/hi/programmes/panorama/archive/506549.stm

- Georgie Sheldon was treated in a locked psychiatric unit.
  and
- Helen McDade - felt accused of causing her child's illness.

So in 2003 one could be forgiven for thinking that the MRC would effect changes to avoid this type of event occurring.

Yet in 2006 the story of Sophia Mirza unfolded - a tragedy allowed to occur as a result of the collective policies of governments, Department of Health, the CMO and MRC and others - a tragedy which should not have occurred.

The status of the MRC response to ME has been poor. Sir Colin Blakemore has been invited to the ME/CFS Conference in May 2007. We are hopeful he will be present and we can start to make progress using the Gibson Inquiry as a springboard for a new initiative.

## Status of Research into ME

Since the MRC Briefing Strategy at least 14 proposals have been rejected by the MRC yet the MRC is currently funding a number of expensive projects - such as the psychiatric trials PACE (£2,076,363) and FINE (£824,129) (see PACE and FINE trials), a study to assess ethnic variations of the prevalence of a CFS-like illness, associations with potential risk factors, and coping behaviours (£162,145). A total investment of £3,180,900. Yet the MRC policies bear little resemblance to the recommendations from their briefing document. Why is nothing spent on biomedical research?

## Status of ME Community

If we feel criticism is validly directed at the organisations which are supposedly there to ensure the health of citizens then we also have to look within ourselves and ask if we could do better. For an illness affecting so many citizens across the world we should be able to mount a more effective and coordinated campaign and it is evident that the ME community needs to work together and organise funding for biomedical research to supplement whatever becomes available from the government.

There are many groups and individuals doing excellent work in the UK and abroad who raise awareness of ME and perform fund-raising events for ME. We need to coordinate all of this and get more people to help us.

IiME's aims are to get adequate funding for biomedical research into ME, proper diagnosis for ME (including adoption by health departments of correct diagnostic guidelines), a co-ordinated long term plan for biomedical research and finally treatment and cure for ME. This is what we believe needs to be delivered and we welcome the chance to work with other groups. This is why IiME and ME Research UK are working closely together on many issues - amongst them ME Awareness Month.

IiME would like see as many ME support groups as possible to be represented at the International ME Conference on 1st May 2007 - especially at Day 1 where we can work together to create a new spirit of cooperation.

We are hoping that a number of our UK and international contacts will be present so that we can work together on creation of an international alliance of people dedicated to campaigning for positive changes for people with ME and their carers. Already we have possible user groups attending from Ireland, Norway, Sweden, Germany and USA as well as from within the UK. Last year eight countries were represented at the conference and the DVD of the conference sold in 16 countries. We hope this year we can improve on that.

The agenda for Day 1 will involves subjects which we hope ME Support groups can work together on - ME Protocols, plans for a National ME Blood & Tissue Bank, International links and cooperation, experiences from other countries in their opposition to NICE, and linking together of campaigns for raising of awareness of ME and funding of biomedical research. If your group wishes to have a topic discussed then please contact us.

ME Awareness Month should be a time that all ME Support groups can work together and the conference provides this opportunity - and not just in the UK but across the world.

## IiME Campaign - CMO and ME As a Notifiable Illness

After writing several times to the Chief Medical officer (see here) IiME has now been given an opportunity to meet the Deputy CMO. We have an appointment at the end of the month where we will press our argument that ME needs to be made a notifiable illness within schools.

We are very pleased that Professor Malcolm Hooper has also agreed to attend this meeting as we attempt to get some agreement on other issues.

It is a pity that pwme and their carers have to constantly battle to be heard. However, we won't give up and we shall report on our meeting in a later newsletter.

## The Gibson Inquiry

IiME have submitted our response to the Group on Scientific research into Myalgic Encephalomyelitis to Dr. Ian Gibson's office (see here). We feel it needs to be used to support an effort to effect the changes recommended by the Inquiry.

Just at the time this newsletter was about to be distributed then news came of Dr. Gibson writing to the CMO, MRC, Minister for Work, the Treasury and to the Academy of Sciences (see here).

We are also pleased to have seen the correspondence from Countess Mar who has written to Professor Richard Baker - the chair of the NICE Draft Guidelines on CFS/ME - in forthright terms. An extract here -

> "I doubt that you can have avoided being aware of the tide of opposition to the Draft Guidelines from members of the ME community. I wonder whether you can comprehend just how hurt and insulted they feel?
>
> For years they have been denigrated and denied medical treatment and benefits that the rest of our population expect when they fall ill. They have pinned their hopes on the integrity of NICE, hoping that, at last, someone with influence will listen to them and recommend decent medical, financial and social care provision. Instead they find that all the old prejudices are recycled; their predicament is watered down by the inclusion of people who do not suffer the same illness: there is still an insistence that, like rats on a treadmill, they can be 'trained' to respond as certain professionals who, for some strange reason have been accorded undue deference, think they should.
>
> That age-old instruction to doctors to: 'Listen to the patient: they will probably tell you the diagnosis.' seems to have been forgotten in this welter of almost incomprehensible paperwork."

So there is support. Now would be a god time for everyone to contact their MPs to gain further support.

Both Dr. Gibson and Countess Mar will be in at the ME Conference in May.

## ME AWARENESS MONTH MAY 2007

Invest in ME and ME Research UK are working together to promote ME Awareness Month 2007. Our Events calendar is awaiting news of any events which are planned. Already friends of IiME are planning events during May and we hope to provide more news of these events as soon as they are finalised.

The IiME newsletter is reaching every corner of the UK and over twenty countries - so please let us know of any events planned across the world. Our events diary will be updated accordingly - see here.

## ME / CFS Conference

There has been a slight change to our agenda for the May conference.

Unfortunately Dr. Leonard Jason has had to cancel his participation in the conference due to other commitments but has promised to work with us and we hope he will be present at the 2008 conference.

However, we are pleased to welcome two new presenters to our line up - Dr. Nigel Speight and Professor Martin Pall will be joining the event.

Dr Speight is well known in the UK and abroad and will be covering ME and paediatrics.

Professor Pall works in the School of Molecular Biosciences at Washington State University USA. He also has a book being published at the time of the conference (Explaining "Unexplained Illnesses": Disease Paradigm for Chronic Fatigue Syndrome, Multiple Chemical Sensitivity, Fibromyalgia, Posttraumatic Stress Disorder, Gulf War Syndrome and Others).

All of the presenters at the conference are well-known throughout the ME community, and beyond. We have updated our conference agenda to reflect the changes. We are also still getting requests to speak at the conference so the line-up may be amended as we refine the agendas.

We hope also to start a delegates' page so that people attending the conference can tell us about themselves and inform fellow delegates prior to the event.

Use the conference details page to keep up to date with the latest information or use the IiME site map feature to browse the IiME site, or the web for more. More details here.

Home | Registration | Details | Venue | Awareness Month | Conference 2006

## Sponsor a Medic

A further appeal to ME Support groups to help get more GPs, paediatricians and other healthcare professionals to the conference in May. This applies also to non-UK groups. At last year's conference we had several physicians in attendance from outside UK.

IiME are offering a discounted rate to healthcare professionals who are being sponsored by an ME support group or charity - one day for £75 or both days for £150. And with CPD accreditation pending for the conference the conference can be added to your GP's training quota.

More details are here and, to facilitate this, we shall soon have an information pack which may be downloaded and distributed to your local PCT, GP surgery or hospital.

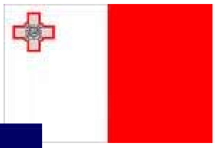
## Sophia's Story - Your Responses

As people may know Sophia's mother, Criona, has instigated proceedings with the General Medical Council against 6 doctors involved with Sophia's case. The GMC will not make a decision until the end of March as to whether there is a case to answer or not.

We are still getting emails from friends commenting on Sophia's story - see here. Please feel free to add your comments - they mean a lot to Criona and her family.

We have also added the Marshall/Williams/Hooper article ***What is ME? What is CFS?*** as a page on our info library section - see here.

## ME Story



We include a story from Malta this month

**From Rebecca:**

“After hearing my story, viewing my countless blood tests, x-rays, internal examinations and MRI results and a thorough examination, the neurologist immediately suspected that I was suffering from ME. He asked me to look up the internet and check if all my symptoms were recorded on an ME patient's list of complaints."

Read more here

## Dr. Byron Hyde and Thyroid in ME

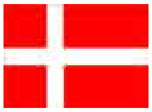
At last year's ME Conference Byron Hyde mentioned the prevalence of Thyroid malignancies in pwme. Dr. Hyde is one of the handful of world physicians with such a long experience of examining only ME, CFS and fibromyalgia patients.

Dr. Hyde is one of the few physicians who have been doing a total technological body assessment on ME and CFS patients. This has revealed an incredible amount of information on the differences between ME and CFS. Without extensive examination Dr. Hyde feels pwme will never know why they are ill and one will never get to the bottom of this group of illnesses. Dr. Hyde writes

> "One of the papers I wanted to give (at the IACFS conference) demonstrated that cancer of the thyroid was found in 1-15 cases per 100,000 in the general population and in **6,000 cases per 100,000 in ME patients**, and in all of the cases there was severe Central Nervous System changes involving not only the cortex but also the subcortical structures. The cancer in all cases developed after the ME and the ME was not caused by the cancer".

Dr. Hyde will be able to elaborate more at the ME Conference in May.

## A History of ME



From Denmark we received this from Lajla Mark - we are happy to pass on this link if you would like more information of the history of ME -

> "These days, when the terms CFS and ME is a rather hot topic, I would like to draw your attention to this newly updated essay on ME and ME/CFS History explaining and documenting the development of ME into CFS and how the current standing is by both WHO and CDC."

Lajla's document can be found at here.

## ...and finally a New Year Calendar

Thanks to Regina Closs and Hans-Michael Sobetzko for providing this calendar which may be copied from the web site (please see the comments in the calendar itself).

Download the calendar here.

**Contacts:**

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