



NEWSLETTER

Welcome to Invest in ME's September 2009 newsletter.

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H1N1 Influenza Virus

The Chief Medical Officer has responded to our request for advice for ME patients as to whether he considers people with ME to be more at risk from the H1N1 strain of the flu virus, and whether Tamiflu will be immediately available if requested. His reply is [available here](#).

The CMO states that ME "is not known to increase the severity or duration of community acquired infections" and he is "not aware of evidence that ME leads to more severe and complicated influenza, and ME is not a condition which leads to the inclusion of sufferers in the population groups offered vaccination for seasonal influenza".

The CMO's web pages which describe the "population groups" offered vaccination as -

Following advice from independent expert committees including the Joint Committee for Vaccination and Immunisation (JCVI), the following groups should be prioritised for vaccination in the following order, once the vaccine has been licensed:

- i. individuals aged six months and up to 65 years in the current seasonal flu vaccine clinical at-risk groups
- ii. all pregnant women, subject to licensing conditions on trimesters
- iii. household contacts of **immunocompromised** individuals
- iv. people aged 65 and over in the current seasonal flu vaccine clinical at-risk groups.

These groups were selected because they are at highest risk of severe illness.

[<http://tinyurl.com/mke5qk>]

We know that the Department of Health officially classes CFS/ME as "a chronic neurological condition". The NHS website includes chronic neurological diseases among high risk groups needing preferential treatment - see the influenza immunisation programme 2009/10 in



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Annex 5 under Clinical Risk groups is included Chronic Neurological disease -
[http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_097535.pdf]

That qualifies ME as one of the high risk groups. The CMO states in his web page -

that any vaccine for H1N1 would be given to "household contacts of immunocompromised individuals"

yet he also states in his letter to Invest in ME -

that ME " is not a condition which leads to the inclusion of sufferers in the population groups offered vaccination for seasonal influenza".

There is an obvious and dangerous inconsistency here.

There is a great deal of research indicating that patients are "immunocompromised" and, if the CMO had come to any of our conferences, he could have been made aware of that from the leading experts on ME. The role of enteroviruses and herpes viruses in this illness has had much peer-reviewed research of which the CMO ought to be aware. These are known to persist in ME patients.

We have written back to the CMO [[click here](#)] to determine if he would like to revise his position and his statements on this subject.

Conference DVD

The DVD of the conference has now been distributed to almost twenty countries. Hillary Johnson has reviewed the IiME conference in May - available on her web site - <http://oslersweb.com/blog.htm?post=623914>.

For those in Australia or New Zealand who wish to order the DVD we would like to mention that the Alison Hunter Memorial Foundation has taken delivery of a number of the DVDs and you may also order from there - see www.ahmf.org.

Details on ordering the DVD are here ([click here for details](#)).

IiME ME Information Package

Invest in ME have been awarded a grant to supply ten Hampshire libraries with an ME information package consisting each conference DVD (2006 - 2008), a Lost Voices book and the Canadian Guidelines.



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We hope to add more such packages for other libraries in the future.

We still have some copies of the Journal of IiME Volume 3 Issue 1 available (the May 2009 conference version). If you would like a copy we are offering them for £2 plus p&p. For those of you who feel a copy of the Journal being sent to your GP or MP would be of help to you and your situation then we are willing to send the Journal directly to your GP/MP. As we don't have funds to print more copies then this will be on a first-come-first-serve basis.

Response to E-Petition to Prime Minister

We are in the process of replying to the to the Prime Minister's (read Department of Health's) reply to the e-petition (mentioned in our June newsletter).

We suggested to the Prime Minister that a sizeable portion of the electorate could be directly or indirectly affected by ME and the lack of progress due to government policies. With a year to go before an election in the UK maybe now is an opportune time to begin a page detailing the responses from the different political parties - [click here](#).

We emailed the other main political party leaders to ascertain their views on the Prime Minister's response and have documented the replies which we received from David Cameron (Conservative) and Nick Clegg (Liberal Democrats). These responses aren't adequate and we'll be requesting more precise details on policy toward ME over the coming months.

You are welcome to send us any examples of replies from MPs on this subject and we can publicise the responses in the run-up to the election.

Response from CMO to 12th May Appeal

Invest in ME have been contacted by the Long Term Conditions team following our May 12th appeal to the CMO to champion the cause of people with ME.

We are in the process of setting up a meeting to discuss our view of what needs to be done, what is missing and how we might achieve our objectives.

DLA

Plans to change the way the Disabled Living Allowance is provided are on the way following a government Green paper. From Steve Donnison (Benefits and Work Publishing Ltd) -

A government green paper has revealed proposals to stop paying 'disability benefits, for example, attendance allowance' and hand the cash over to social services instead.



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Under the plan, current claimants would have their disability benefits converted to a 'personal budget' administered by local authorities and used to pay for services - not to spend as they wish.

Once the green paper consultation period ends in 100 days time, if an almighty row has not been raised, it is likely that both major political parties will see the lack of outrage as a green light to end both DLA and AA.

We're looking for a minimum of 1,000 claimants, carers and support workers to join our campaign to save these benefits from being abolished.

Find out how you can take part from this link:

[http://www.benefitsandwork.co.uk/disability-living-allowance-\(dla\)/dla-aa-cuts](http://www.benefitsandwork.co.uk/disability-living-allowance-(dla)/dla-aa-cuts)

We know that many people will take false comfort from the fact that, unlike AA, DLA is not specifically named as being for the axe. But if the government was planning only to abolish AA it is extremely unlikely that they would refer constantly throughout the green paper to 'disability benefits', a term which includes not just AA but also DLA.

Others will dismiss this as just another idle discussion document and our concerns as scare mongering.

But it's much more than that.

36 meetings have already been organised around the country for people working in government and the caring professions to meet to be told about the setting up of a new National Care Service which would oversee the system. In addition, a stakeholders panel of more than 50 voluntary sector organisations, trades unions and academics has been established to offer advice to the government.

Some organisations and individuals, such as RNIB and welfare rights worker Neil Bateman writing for Community Care magazine, have already voiced their alarm.

But not every disability organisation is opposed to the proposals and some even agree with them.

In a press release, Disability Alliance has welcomed the publication of the green paper and said that it 'looks forward to working alongside Government and all the other stakeholders in bringing these plans into fruition'. They have even said that they agree that there is a case for 'integrating disability benefits such as attendance allowance' into the new system.

One thing everyone does seem to agree on is that huge cuts in public spending will have to take place in the next few years as a result of the credit crunch and global recession.

Political parties are desperately looking for the softest targets to be the victims of these cuts. Dismissing the green paper's proposals as hot air and not worth worrying about could be the costliest mistake you ever make.



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MRC Finalised Terms of Reference

The MRC finally published their terms of reference for their proposed panel under Professor Stephen Holgate. Our thanks to Suzy Chapman [<http://meagenda.wordpress.com>] for passing this information on and for continuing to request information to be provided by the MRC under the Freedom of Information act. The next MRC next meeting will be in November [click here](#).

The terms of reference are of the generic vagueness that hampers ME research. Two years have passed since this panel was conceived and so far this is all that the MRC strategy amounts to.

The lack of urgency would be appalling if one really believed that this is going to achieve anything. But haven't we been here before? Going back to 2002 -

<http://news.bbc.co.uk/1/hi/health/2581153.stm>

What happened to the clinical trials to evaluate the merit "of different treatments", "the use of imaging technology to determine whether ME/CFS is linked to physical changes", "an examination of the possible role of the central nervous, immune and hormonal systems"? Fine aims - needless to say nothing happened.

We know what happened to the "psychological studies" - the vested interests within the MRC who referee all proposals subsequently decided to fund the PACE and FINE trials.

We do not believe the MRC will ever treat ME seriously until they are embarrassed or forced into doing so. The tardiness of the whole MRC approach to sensible scientific research into ME leads us to believe the latest initiative is another ploy to delay treating ME research seriously. It will prolong the discussion of ME biomedical research under the guise of a comprehensive strategy.

In two years the MRC panel have got precisely nowhere. Contrast this with what the Whittemore-Peterson Institute has achieved in those same two years and look at the promise the WPI holds compared to the lacklustre and barren commitment from the MRC.

The MRC declined offers facilitated by Invest in ME to visit the WPI. We can only thank the stars that we have the WPI's work which will make the MRC "strategy" and their panel of experts redundant long before it ever produces anything of real substance.

ME Story - ME Entrenchment

What filled me with resentment and embarrassment was that my father and in turn many of his close friends and colleagues were in positions in which they could have propelled ME/CFS forward into main stream medicine and



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greater acceptance. The way he treated of me was merely an act upon one person -- his denial that ME/CFS was real and his refusal to help get understanding of the illness and increased ME/CFS research into main stream medicine was an act of medical irresponsibility inflicted upon all people who have ME/CFS. That is what I could never forgive him for.

Long time ME advocate, John Herd, wrote in our 2008 conference Journal of IiME [<http://tinyurl.com/5bzzxx>]. John has given us permission to repost his article ([click here](#)) on Medical Entrenchment and ME/CFS - clearly showing the dangers of biased and heavily entrenched views on ME research.

My Sister Sophia - Before ME

Roisin Mirza, Sophia Mirza's sister, has created a You Tube film of Sophia before she became ill from ME - [click Here](#). The film shows something of Sophia when she was well and it will give people an idea of what she was like.

Fund Raising for ME

With John Herd's last sentence in the article above in mind ["I beg people to give till it hurts, for ME/CFS hurts a lot more"] we have set up a fundraising page to show events occurring or which have occurred - [click here](#).

If you'd like to help raise funds for Invest in ME then on 6th September Crystal Igliakowski will be running the Adidas Women's 5k Challenge Sunday 6th September 2009 on behalf of Invest in ME.

If you'd like to sponsor her, please go to her fundraising site.

<http://fundraisers.everyclick.com/info.xq?id=1177146&fundraiser-name=crystal-igliakowski>

Invest in ME have set up a Biomedical Research Fund (announced in January) which we hope to say more on over the next months.

And another reminder that the Whittemore-Peterson Institute hold their annual fundraising gala on 12th September. The WPI are well worth supporting even if one can't attend the actual event [<http://www.investinme.org/helpus.htm#Donate-to-the-WPI>]. President of the WPI, Annette Whittemore's daughter Andrea, has commented on [IiME's facebook](#) -

"Please buy a ticket to I Hope You Dance 2009 or donate what you can. The event benefits the Whittemore -Peterson Institute being built at the University of Nevada Reno. It takes place September 12,2009 at the Peppermill in Reno from 5:30-10:00 pm. Go to www.wpoinstitute.org for more information! And please become a Friend of the Whittemore



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Peterson Institute at Friends of the [Whittemore Peterson Institute facebook](#) page.
Thank you
Andrea"

Best wishes to all

Invest in ME

Support Invest in ME - support biomedical research

Please help us by using Everyclick whilst surfing the web. INVEST IN ME is listed on **Everyclick** the search engine that helps charity.

Please go to <http://www.everyclick.com/uk/invest-in-me/396708/0> to do all your searching as this helps us continue campaigning for ME/CFS patients and their families.



Contacts:

All inquiries to Invest in ME - info@investinme.org

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Support ME Awareness - <http://www.investinme.org>

