The UK Rituximab Trial for ME

Professor Malcolm Hooper and Margaret Williams

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The charity Invest in ME has provided a truly remarkable opportunity to address one of the biggest medical scandals in history and to remove what in 2007 Alex Fergusson, Presiding Officer (Speaker) of the Scottish Parliament, referred to as "the cold grip of psychiatry" on myalgic encephalomyelitis (ME), which he said was "still far too deeply rooted in the world of ME" (http://www.meactionuk.org.uk/Defiance_of_Science.htm).

Now, however, despite the power and control of the psychiatric lobby, thanks to Invest in ME and the invaluable support of Jonathan Edwards, Emeritus Professor of Connective Tissue Medicine at University College, London, (world-renowned for his work in B cell immunology and as lead researcher in the clinical trials of rituximab for rheumatoid arthritis), the neuro-immune disease ME is at last about to enter the realm of mainstream medicine in the UK under the guidance of Professor Edwards himself.

Invest in ME are at the forefront of international biomedical research and have by sheer determination and effort managed to put things in place for a trial of rituximab to begin on ME patients in the UK. They recognise the urgency of the situation and know that many ME patients do not have the luxury of time. The charity already has the facilities in place, including suitably experienced researchers (Professor Jo Cambridge is now principal researcher at UCL, and the ME trial will involve the same team working under her that carried out the rituximab research in RA).

The Clinical Trials Unit at UCL is already working on the protocol, and Invest in ME have agreed with Professor Edwards that the protocol will be externally reviewed even though the UCL team will make sure it is cast-iron by their own internal reviewers.

Invest in ME have been told this trial could start relatively quickly if the charity had funds available. Such an opportunity must not be lost. However, this will not happen without substantial funding.

We therefore ask everyone who is able to do so to donate whatever they can afford, in order that the UK rituximab trial can get under way as quickly as possible whilst the excellent facilities and committed staff at UCL and the active support of Professor Edwards remain available, so that ME can finally be recognised as the devastating multi-system neuro-immune disease that it is and - most importantly -- so that sufferers may at last have some hope of alleviation of their suffering.

Invest in ME have assured us that all donations to the rituximab fund will sit in a separate account which is totally ring-fenced, and should the trial not proceed, the following statement on the IiME website will be honoured –

What Happens With These Funds If The Project Does Not Go Ahead:

If the rituximab project does not go ahead for some reason then the funds raised will be transferred to the IiME Biomedical Research Fund to fund other biomedical research projects which are attached to our proposal for an examination and research facility based in Norwich Research park in Norfolk, UK. These funds will only be used for biomedical research into ME.

- http://www.investinme.org/IIME%20Statement%201306-01-faq.htm

A UK trial of rituximab is essential to move ME out of the realm of psychiatric dogma and into the realm of medical reality.

Information on how to donate can be found on the Invest in ME website: www.investinme.org

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Invest in ME wrote in their Facebook group: Thank you Margaret Williams and Professor Hooper. Lovely endorsement from those to whom the ME community will be eternally indebted.

http://investinme.org/IiME%20ME%20Facebook.htm

From the team at Let's do it for ME: Our grateful thanks to Margaret Williams and Professor Hooper for their unwavering advocacy for people with ME and for this clear statement of support.

http://blog.ldifme.org/2013/08/statement-by-professor-malcolm-hooper.html