



Charity Nr 1114035

# *Invest in ME*

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## **A Status Update for the IiME/UCL Rituximab Clinical Trial**

When Invest in ME announced in June that we were planning a UK trial of rituximab for ME there was a great deal of interest raised.

The rituximab trial follows the exciting work which has been, and is being performed in Norway by the Haukeland University hospital researchers Professor Olav Mella and Dr Oystein Fluge.

Since these excellent Norwegian researchers came to present at the Invest in ME conferences in 2011 we have followed their progress, and invited them back every year for our BRMEC researchers meetings and IIMEC\* conferences.

The research work has been backed up by impressive and dedicated patient advocacy by the Norwegian ME Forening which has raised the profile of ME in Norway and throughout the world. Their tireless work has encouraged IiME. The more recent success of the ME and You campaign to raise funds for the Norwegian research has created real hope amongst patients.

At the IIMEC7 conference IiME announced our intention to work toward establishing a clinical trial of rituximab in UK [[1](#)].

In updates published through July and August IiME has stated that all that is required for the trial to proceed is the funding. In the spirit of cooperation we have stated that support for the trial was welcome and that IiME would acknowledge all such support.

Our supporters have risen to the occasion and valiantly supported the IiME/UCL trial with wonderful enthusiasm. The imaginative Let's Do It For ME campaign has continued to produce ideas to raise funds and awareness and The MATRIX is an example of a unique method of achieving both.

We have had donations from around the world, ranging from £1 to £3,000. We have had a very generous donation of £25,000 from a foundation and this has allowed the funds raised to grow to £59,000 in a very short space of time. We have also had fantastic moral support from a great many.

As such, IiME and our supporters have managed to initiate and organise something which many thought was not possible.

IiME made it clear from the beginning that we welcomed support for the IiME/UCL clinical trial from other organisations. Our objective is to ensure that a clinical trial of rituximab is allowed to be performed by the best researchers



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possible and to ensure that this trial makes a valuable contribution to the collective research pool. This is why we have been keen from the beginning, and since our inception as a charity, to initiate collaboration with other like-minded international charities and organisations, and build collaborations between ME researchers across continents.

We believe in achieving results by the most direct method, where possible. For IiME the issue of making rapid progress in ME research is important, it is personal. The need is here - the need is now.

We arranged a specific web site which has been set up to inform on all aspects of the UK rituximab trial. This is at -

[www.ukrituximabtrial.org](http://www.ukrituximabtrial.org)

and we reiterated the current status [2]

- We have the facilities available.
- We have the researchers available.
- We have the best expertise possible available.
- We have the means of fundraising for this trial available (see The MATRIX [3] ) and we have a campaign to raise funds
- We have emphasised that the only remaining element required was funding

We have reached this position thanks to the vision, efforts and help from Professor Edwards, Dr Cambridge, UCL and our supporters.

Thanks to the amazing efforts of our supporters we have been able to agree already to initiate a preliminary study on B-cells at UCL.

Professor Edwards will shortly visit Bergen – a trip arranged by IiME as part of our collaborative attempts to unite researchers and build on experience.

We can now announce that IiME have been given a pledge of £200,000 from a foundation to supplement the amount we have raised already.

This would bring our rituximab fund to almost £260,000 – that is over two-thirds of the requirement for the clinical trial to proceed.

The foundation has two conditions to this pledge

- That IiME continue to be the lead patient organisation steering this trial
- That IiME continue to raise funds for the remaining £90,000 that is required for the full trial to proceed



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The trustees of IiME have accepted these conditions willingly.

We are thankful and grateful for this extraordinarily generous offer from the donating foundation. It is an amazing gesture from compassionate and caring people who want to make a difference. It allows the hopes of many patients to become a reality – allows a vision to be maintained that there is a future for ME patients and that we, patients and families, can make a difference.

We have communicated this to the UCL team with whom we are working to make this trial a reality.

We are now distributing this information to our supporters.

There were many who doubted that IiME and our supporters could achieve this. Though we knew this would be a daunting task we have never doubted it was possible.

We continue our efforts to raise the remaining funds.

To our supporters who have been with us since the beginning and everyone who has contributed in so many ways to this trial we want you to know this is your result. It is what you have achieved. It is what we have achieved together.

We thank all those who are supporting this trial and we will continue to provide information on the status of the trial as we progress.

We continue to welcome support. Please contact IiME directly if you or your organisation would like to assist or contribute.

If anyone would like to ask any questions about the UK rituximab trial then please use the Contact form on the rituximab web site [[4](#)].

A status is available [[5](#)].

With this trial we can take a huge leap forward in ME research.

If you are also interested in the other research projects that Invest in ME is organising and/or funding please see our main website and free newsletter [[6](#)].

Let's Do Research! Let's Do It For ME!

Thank You.



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## **References:**

- 1 <http://www.investinme.org/Rituximab%20news-Aug13%2001.htm>
- 2 <http://www.ukrituximabtrial.org/IIMEUKRT%20Summary.htm>
- 3 <http://www.ukrituximabtrial.org/IIMEUKRT%20Matrix.htm>
- 4 <http://www.ukrituximabtrial.org/IIMEUKRT%20Contact.htm>
- 5 <http://www.ukrituximabtrial.org/IIMEUKRT%20Summary.htm>
- 6 <http://bit.ly/1f7k9y7>

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