



UK Centre of Excellence for ME

How much are we trying to raise at the moment and will the money given mean the centre can be opened?

An initial research project (genome sequencing and stool samples for gut research) was proposed which could cost up to £100,000, so that was the initial target for this campaign. This research would give a solid foundation for future research.

Does all the money raised by this campaign go to the centre?

Yes - all donations arising from this campaign are made directly into Invest in ME's Biomedical Research Fund (BRF) to help get this initiative off the ground.

What happens if the centre doesn't open for some reason beyond Invest in ME's control?

If the current project does not result in an examination and research facility being set up in Norwich then Invest in ME's commitment is to try elsewhere in the UK.

If it becomes impossible to initiate the planned research and examination facility elsewhere in the UK then the charity trustees will seek advice from our research contacts and decide on using the funds raised for this proposal for other high quality research purposes.

These funds will, however, only be used for high quality biomedical research.

Is there a date by which the money needs to be raised to achieve this?

Currently there is no specific date set but we would like to have the research projects started as soon as possible.

Is it just a matter of not having funds or are there other hurdles?

The steering group is currently attempting to negotiate regarding agreement to hold clinics for examining and treating patients at the Norfolk and Norwich University Hospital.

This issue can be overcome as the Norfolk PCT has stated that space is not a problem for examinations by the ME consultant and there will be a place to perform these. The hope is to convince the university hospital to allow this to be started there but a local community hospital has been mentioned as being available to allow these examinations to be initiated.

Are there other funding sources for the centre, e.g. NHS?

There are other sources of potential funding.



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A verbal commitment of support has been received and other potential sources have been discussed. Work is continuing to obtain other sources of funding and we are hopeful of obtaining more funding in the future.

How will patients be selected for research?

Patients would be assessed using the criteria specified by the ME consultant and in agreement with the researchers. Virology and immunology will be the key to examining patients.

How can we be sure that we are donating to high quality research?

The charity and the Let's do it for ME campaign organisers, are confident that the research will be cutting edge and of the highest quality, bearing in mind that the aim is for the research to translate into treatments for ME patients. The list of speakers at Invest in ME's annual conferences is testament to the calibre of the researchers the charity liaises with. The research facilities at the University of East Anglia are first-class, as are the UEA researchers themselves, one of whom chaired a "corridor conference" session with all the other researchers at the annual conference in London in May. DVDs of the conferences are available to order from Invest in ME's website and these will show the quality of researchers.

What will the research be?

The research highlighted in the proposal, along with looking at gut inflammation, involves genome sequencing, which is the latest thinking in how to go about research - in USA, renowned pathogen hunter Dr. Ian Lipkin, specialist Dr. Nancy Klimas and also Whittemore Peterson Institute for Neuro-Immune Diseases are all suggesting the same approach. This is not to say that this would be the only type of research needed - the aim is to build on this but the research has to start somewhere and so the researchers will begin afresh with the best approach. This research proposal would build a strategy of research which would involve patients, clinicians and researchers working together

Are there other organisations supporting this, e.g. other charities and the NHS?

Internationally, the proposal for the centre has full support from the members of the European ME Alliance, from the Whittemore Peterson Institute in USA and also from Australia. Various regional, local and on-line ME patient groups are supporting this campaign, some with awareness and fund-raising activities. You can read comments of support in the Let's Do It for ME blog Guestbook.



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It is hoped that the treatment area for the centre will be based at the Norwich and Norfolk University Hospital. The PCT has stated that they will fund the examinations and Invest in ME has been offered support by the Primary Care Trust Research Advisor.

How long (if the money is raised) before we get a centre?

This will depend on the initial proposals, the ME examinations (frequency) and future developments in resources and funding.

The important points are that we need to ensure that people with ME can be examined by a consultant who understands the disease, and a diagnosis made using correct internationally accepted guidelines.

ME patients need to be able to be entered into biomedical research and a strategic approach to research needs to be initiated.

So this will be an evolving development based on the support of the NHS, the ability to attract and fund biomedical research.

Once a model is established and correct protocols developed and used then this can be taken to the next stage.

How long before the centre would take patients?

Patients would initially be taken from Norfolk as Norfolk PCT has promised to fund these examinations and treatments.

We would expect that developing the examinations in scale and frequency would then open the doors for referrals from other areas.

Once this development is continuing then other ideas can be generated.

Having a single place where proper examinations, diagnosis and biomedical research is being performed will allow collaborative work to be started and sharing of information with other areas who wish to use the experiences from this centre.

How will patients be referred and can patients be referred from anywhere or will they be local?

In the UK these would be via the NHS. One could envisage in the future that referrals could also be made from within Europe, according to European regulations.

What will the money we raise actually be spent on - will the clinicians be employed on a private basis so is some of the funding we are raising going on doctors' fees?

We expect the NHS to cover clinician's fees.



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With limited funding from MRC and reluctance by most authorities to do anything for people with ME we must utilise existing facilities and services.

The money raised from fundraising would go to high-quality biomedical research.