



## Proposed Centre of Excellence for ME Patients in Norfolk

### Executive Summary for MPs

**STATUS September 2011**

#### Background

- Seriously inadequate standard of medical care for ME patients in UK
- Very little funded UK biomedical research into condition
- Confusion between ME and 'chronic fatigue' has led to unscientific research and ineffective treatment regimes
- NHS resources focus on symptom management therapies whilst underlying condition left untreated
- Medical professionals lack understanding of and training in ME - serious risk of mis-diagnosis and missed diagnoses
- International research has revealed much about biomedical basis of ME
- ME now identified as both highlighted area and high priority by MRC
- ME is leading cause of long-term absence from school due to sickness for students and teachers

#### Project Outline

- Biomedical research and treatment institute for ME in East Anglia, based in Norwich within the Norwich Research Park utilising and based on university and institute facilities and resources
- Hub of scientific and clinical excellence for ME within Europe
- Research arm to be funded by private/charitable donations
- Clinical diagnosis and treatment arm to be funded by PCT/GP consortia

#### Service Commissioning

- GP referral, via normal NHS channels
- Consultant physician to diagnose patients according to international scientific criteria
- Based at Norfolk and Norwich University Hospital, subject to agreement
- GPs with special interest to be linked to Institute
- Treatment of patients based on up to date biomedical research findings



# UK Centre of Excellence for ME

- Hub and spoke model: dissemination of expert knowledge to GPs and ME clinics nationwide
- Out of area referrals included
- Correctly identified patient cohorts considered for Institute research projects
- Training opportunities for medical students and other consultants, nurses etc.

## **Invest in ME**

- UK charity campaigning for biomedical research and treatment of ME
- Founder member and current Chair of European ME Alliance
- Organises annual international CPD-accredited international ME Conference
- Holds worldwide contacts with ME organisations, physicians and researchers

## **Research**

- Based at Norwich Research Park, including University of East Anglia and The Genome Analysis Centre (subject to formal agreement)
- Advanced research, initially using virology and immunology
- Key component: accurate definition of patient cohort, giving scientific validity to results
- Translational research - potential for direct patient benefit
- Dovetails with MRC identification of ME as priority area and recent £1.5m funding proposal
- Initial projects: TGAC genome sequencing facility to identify known/unknown viruses in patients (under discussion with UEA researchers). Allied project:: link between ME and gut inflammation
- Includes cooperation with other national/international research facilities (network already in place)

## **Benefits**

- Unique opportunity to establish European hub of scientific and clinical excellence
- Attraction of international interest and research funding to East Anglia
- Early and correct diagnosis
- Establishment of clinical trials
- Development of effective treatments, leading to highly significant public savings
- Hub and spoke' model to address seriously inadequate levels of clinical service for ME in East Anglia and nationwide



# UK Centre of Excellence for ME

- Development of network of domiciliary services to support severely affected patients (currently seriously neglected)
- Savings on existing consultant referrals and staff - ME examination focused in one area.
- Financially viable – Institute can start small and grow as further funding becomes available

## **Current status**

- All elements of the Institute model are now in ready to be put in to place (subject to formal agreement) with the exception of Norfolk and Norwich University Hospital, which is currently declining to provide a service locally as they do not feel that they “can provide a satisfactory high quality service on the basis proposed” – despite offering no service currently to ME patients. Norfolk PCT has stated that space is available elsewhere in Norwich to allow the examinations to be started.
- Invest in ME is therefore asking Norfolk MPs to engage actively with this project with a view to securing this final, and vital, element of the project.

Further details:      Invest in ME

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