

East Anglia ME Patient Partnership (EAME)



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19 October 2006

Mr Bernard Williamson, Chairman
Mr Michael Stonard, Chief Executive Officer
Ms Linda Clark, Head of Intermediate Care &
Rehabilitation/Chair, Norfolk & Suffolk ME/CFS Partnership Board
Mr James Elliot, Director of Commissioning
Great Yarmouth & Waveney NHS Primary Care Trust
1 Common Lane North
Beccles
Suffolk
NR34 9BN

Dear Mr Williamson, Mr Stonard, Ms Clark, Mr Elliot,

The future of the Norfolk and Suffolk ME/CFS Clinic

East Anglia ME Patient Partnership (EAME) provides a consultative and liaison forum for the various patient support groups in Norfolk, Suffolk and Cambridgeshire¹ - who in turn work to assist the many hundreds of ME/CFS sufferers in our three counties. We were very sad to hear of the retirement of Drs Terry Mitchell and Anne Gerken from the Norfolk & Suffolk ME/CFS clinic based at the Lowestoft hospital and provided under the aegis of the Waveney PCT. Dr Mitchell (Department of Health designated CNCC) and Dr Gerken will be missed by many patients and their 20 years of clinical experience, specialist expertise, and professional generosity will be a hard act to follow. Naturally therefore, we are not only concerned to ensure that the clinic continues to receive adequate resources to continue its work, but we also wish to be certain that replacement staff maintain the ethos and high level of standards set by the current clinical lead.

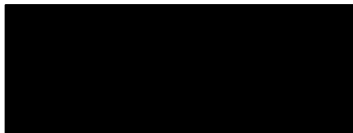
In the spirit of Government exhortations for more patient input into the NHS, we have, through consultative mechanisms within EAME, begun our own preliminary explorations of possible suitably qualified replacements for Drs Mitchell and Gerken. To this end we have had discussions with three very eminent UK ME specialists whose reputations have international standing: Dr Jonathan Kerr, Professor Basant Puri and Dr Nigel Speight. Dr Kerr is the Senior Lecturer in Inflammation and Consultant in Microbiology at St Georges Hospital, University of London who recently hit national news headlines with his pioneering gene research into ME/CFS. He is one of the most highly regarded clinician/researchers within the ME community. Basant Puri is Professor and Head of the Lipid Neuroscience Group, Consultant Psychiatrist and Honorary Consultant in MR Imaging at Imperial College and Hammersmith Hospital, University of London and is also Visiting Professor to the School of Human Sciences at the University of Surrey. He is widely held to be a leading light in ME research/management: having done ground breaking work on the brain chemistry of ME/CFS sufferers using state of the art MR imaging technology. Dr Nigel Speight is without question the most experienced and by far the most highly regarded specialist ME/CFS paediatrician in the country. A former key member of the Chief Medical Officer's Working Group on ME/CFS, he is currently based at the University Hospital of North Durham and working on a follow-up study of Paediatric ME patients.

As you know, Dr Kerr and Professor Puri have now been to visit the clinic and spent some time there with Dr Mitchell and his staff. Both were very impressed with the clinic and have very much expressed a desire to jointly lead the team when Terry and Anne leave. One area where they felt the clinic could benefit from some additional consultant input – if only for two or three hours on one day per month – was that of specialist ME/CFS paediatrics. We are very fortunate therefore that the leading UK ME/CFS paediatrician, Dr Nigel Speight, has expressed an interest in working with Dr Kerr and Professor Puri in Norfolk & Suffolk in this mutually acceptable way. Indeed, as well as presenting very exciting possibilities for continuing and building upon the clinic's good patient care and management provision, Dr Kerr, Professor Puri and Dr Speight are keen to explore the possibilities of involving our patients in ongoing and highly important research work elsewhere - as well as engage in regional professional training and education programmes. Crucially, it is envisaged that all this would be done within the budget levels currently afforded to Drs Mitchell and Gerken.

We believe that we are very fortunate indeed that three such highly prestigious clinical/research specialists have shown an active interest in our regional clinic. Clearly, this not only has potential to bring great benefit to patients but also to increase the standing and profile of our local NHS Trust. We therefore wish the PCT/local NHS management to both consider the possibility of these three eminent doctors working with us in the near future, and to work closely with the East Anglia ME Patient Partnership on these issues as a matter of some urgency. Please let us have your initial thoughts on these matters and tell us how we, as patients/carers can take forward our input to your decision-making/recruitment process.

For your information we are enclosing curriculum vitae and some recently published research papers from the above gentlemen. Thank you for your attention to this matter. We look forward to hearing from you.

Yours sincerely,



Jeff Brown, Chairman
East Anglia ME Patient Partnership (EAME).

Signed for and on behalf of EAME Executive Committee Members:

Brian Hindle.

Dianne Newman.

Linda Pearl.

Barbara Robinson.

Kevin Short.

Pia Simpson.

Richard Simpson.

Cc: Dr Terry Mitchell; Dr Jonathan Kerr; Professor Basant Puri; Dr Nigel Speight.

Enclosures:

Kerr JR: Curriculum Vitae.

Puri BK: Curriculum Vitae.

Speight ANP: Curriculum Vitae.

Devanur LD, **Kerr JR**. Review: Chronic Fatigue Syndrome. *Journal of Clinical Virology* (2006), doi:10.1016/j.jev.2006.08.013

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Kaushik N, Fear D, Richards S, McDermott CR, Nuwaysir EF, Kellam P, Harrison TJ, Wilkinson RJ, Tyrrell DA, Holgate ST, **Kerr JR**. Gene expression in peripheral blood mononuclear cells (PBMC) from Chronic Fatigue Syndrome (CFS) patients. *Journal of Clinical Pathology* 2005;58:826-32.

Kerr JR, Cunniffe VS, Kelleher P, Bernstein RM, Bruce IN. Successful intravenous immunoglobulin (IVIg) therapy in parvovirus B19-associated chronic fatigue syndrome (CFS). *Clinical Infectious Diseases* 2003;36:e100-6.

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Kerr JR, Matthey DL, Thomson W, Poulton KV, Ollier WER. Association of symptomatic acute parvovirus B19 infection with HLA class I and class II alleles. *Journal of Infectious Diseases* 2002;186:447-452.

Kerr JR, Barah F, Matthey DL, Laing ID, Hopkins SJ, Hutchinson IV, Tyrrell DAJ. Circulating tumour necrosis factor- α (TNF- α) and interferon- γ (IFN- γ) are detectable during acute and convalescent parvovirus B19 infection and are associated with prolonged and chronic fatigue. *Journal of General Virology* 2001;82:3011-19.

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Puri, B.K. (2006) Long-chain polyunsaturated fatty acids and the pathophysiology of myalgic encephalomyelitis (chronic fatigue syndrome). *Journal of Clinical Pathology* (in press).

Puri, B.K., Holmes, J. and Hamilton, G. (2004) Eicosapentaenoic acid-rich essential fatty acid supplementation in chronic fatigue syndrome associated with symptom remission and structural brain changes. *International Journal of Clinical Practice*, **58**, 297-299.

Puri, B.K. (2004) The use of eicosapentaenoic acid in the treatment of chronic fatigue syndrome. *Prostaglandins, Leukotrienes and Essential Fatty Acids*, **70**, 399-402.

1 Beccles & District ME/CFS Support Group

Great Yarmouth & Gorleston ME Support

ME Drop-in Support Group, Yarmouth

ME Support - Norfolk

Peterborough M.E. & CFS Self-Help Group

Peterborough ME Support Group

Suffolk Youth and Parent Support Group

The Cambridge ME Support Group

West Norfolk ME Support