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### [The One Click Group Response – CFS/ME NICE Guidelines](#)

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## THE NICE CUTS

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### [The One Click Group Response – CFS/ME NICE Guidelines](#)

Below is what NICE does not want the educated public to see.

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1. SUMMARY

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Fair and proper representation for ME/CFS labelled patients has not occurred throughout the development of these Guidelines. NICE and the Department of Health have together unethically politically and medically manipulated the composition of the Guidelines Development Group such that at least two-thirds of the selected members had exhibited overt psychiatric bias by word, deed and in print prior to joining.

Concerns in the ME/CFS community have abounded in the way in which ME/CFS labelled patients have been 'represented' during the production of the NICE Guidelines and this is nowhere more apparent than in the selection of the so called three 'Patient Representatives' on the Guidelines Development Group. These have failed to represent their constituents throughout and have not in any way correctly fulfilled their duties as set out in the [Guidelines Manual](#), April 2006.

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**Key Statements Summary**

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Page 5 – From [The One Click Group Response – NICE Guidelines](#) (Full Updated Text)

\* Bagnall et al are now open to charges of research misconduct over the York Systematic Review since information has been skewed and deleted in order to cast the psychosocial treatments such as Cognitive Behavioural Therapy and Graded Exercise Therapy (CBT/GET) in a favourable light, as has been stated in the response by the 25% ME Group for the Severely Affected charity to the NICE Guidelines, with which we concur. This document is available on The One Click Group website at:

<http://www.theoneclickgroup.co.uk/documents/NICE/Charities/NICE%20Concerns%20from%20Kate%20Stewart.pdf>

\* At least two-thirds of the Guidelines Development Group members have exhibited overt psychiatric bias and their support of the psychiatric paradigm on ME/CFS. This is known as politically stacking the deck and it is utterly unethical political and medical manipulation of due process.

\* The One Click Group formally requests that the three Patient Representatives stand down from the Guidelines Development Group whilst others more familiar with the biomedical evidence of ME/CFS stand in their place so that patients may be fairly represented prior to the publication of the final version of these Guidelines.

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\* In this Version September 2006 of these NICE Guidelines and through the Guidelines Development Group consensus refusal to allow bacterial and viral testing upon symptoms onset, NICE is deliberately placing the lives of patients at risk, with the full knowledge of the suffering and sometimes death that this will inevitably cause.

\*\*\*\*\*

**2. INTRODUCTION**

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Page 6 – From [The One Click Group Response – NICE Guidelines](#) (Full Updated Text)

There are broadly two contesting paradigms of ME/CFS: The neurological (biomedical) paradigm, and the psychiatric paradigm. (Appendix 1). The psychiatric paradigm in Britain is supported by various psychiatric researchers such as Simon Wessely, Peter White, Michael Sharpe, Anthony Cleare and Elena Garralda, amongst others. It has been demonstrated to have serious theoretical, methodological **and ethical** flaws.

Proponents of this paradigm refuse to recognise the WHO ICD-10 neurological classification of ME/CFS. **Indeed, they unilaterally misrepresented the term Chronic Fatigue Syndrome as being classified as a mental disorder in the ICD-10, wrongly advising the British government. This was corrected by the Countess of Mar during a House of Lords debate in 2004, with confirmation by the World Health Organisation. (Appendix 1).**

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**4. YORK (2005) SYSTEMATIC REVIEW OF THE CFS/ME MEDICAL EVIDENCE BASE**

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This document is the primary building block on which these Draft Guidelines have been based. **The process employed by Bagnall et al in the production of this Systematic Review amounts to research misconduct.**

To summarise:

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**Key Statement:** Bagnall et al are now open to charges of research misconduct over the Systematic Review since information has been skewed and deleted in order to cast the psychosocial treatments such as Cognitive Behavioural Therapy

and Graded Exercise Therapy (CBT/GET) in a favourable light, as has been stated in the NICE Response to these Guidelines by the 25% ME Group for the Severely Affected charity, with which we concur. This document is available on The One Click Group website at:

<http://www.theoneclickgroup.co.uk/documents/NICE/Charities/NICE%20Concerns%20from%20Kate%20Stewart.pdf>

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## 5. PSYCHIATRIC BIAS – THE GUIDELINES DEVELOPMENT GROUP

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**Professor Richard Baker**, (Chairman) Director, Clinical Governance R&D Unit, Leicester. When giving NICE evidence to the Gibson ME/CFS Parliamentary Inquiry on 10 May 2006 between 3.30pm - 5.30pm, the recorded Minutes of that meeting show this: "Richard Baker pointed to the PACE trial as a good example of work being undertaken within the UK at present. Ian Gibson (MP) pointed to the criticism that has been voiced about the trial and its underlying research, which some have accused of being biased toward a psychiatric model. Richard Baker responded by reaffirming that the cause of CFS/ME is still unknown and that he believed that after talking to PACE researchers, he did not believe this to be the case." From these Minutes it is shown that Professor Baker, the Chairman of the NICE Guidelines Development Group, does not subscribe to the World Health Organisation classification of ME/CFS as a neurological illness under ICD-10 G93.3 and is a supporter of the scientifically fraudulent PACE and FINE psychiatric clinical trials. Please see [The PACE Report](#) that includes the original copy of the PACE Trial Identifier, written by the Wessely School Psychiatrists upon application for the funding of these trials from the Medical Research Council.

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**Dr William Hamilton** has spent the last fifteen years employed by the Medical Insurance Industry and has a track record of overtly supporting the psychiatric paradigm on ME/CFS, maintaining that it is a behavioural disorder.

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**Jessica Bavinton**, Physiotherapy Clinical Specialist (CFS), London, is documented as an overt supporter of Graded Exercise Therapy and psychosocial interventions of a neurological illness. In an article penned by Bavinton in the Kent & Sussex ME/CFS Society Newsletter, Summer 2004 she promoted GET as "...one of the most effective therapy strategies currently known."

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**Dr Esther Crawley**, Consultant Paediatrician, Bath, is the Lead Clinician for the Bath/Bristol Paediatric ME/CFS service. **Dr Crawley** has been in receipt of Major Grants, Contracts and Consultancies in 2003 in the development of this 'CFS/ME' Centre such as:

\* DOH grant for centre for CFS/ME, Co-author.

Competitive funding for administrative centre to co-ordinate care and data collection for adults and children with CFS/ME in the South West, Department of Health grant.

\* DOH clinical service grant, Co-author.

Competitive funding for a new clinical service for children with CFS/ME in the South West, Department of Health grant.

These 'CFS/ME' Centres such as the one in which **Dr Crawley** is lead clinician have been roundly condemned by ME/CFS labelled patients around the United Kingdom in documentation provided by the RiME Group - Campaigning for Research into Myalgic Encephalomyelitis at [www.erythos.com/RiME](http://www.erythos.com/RiME). These CFS/ME Centres exclusively employ the psychosocial regimes of Cognitive Behavioural Therapy/Graded Exercise Therapy (CBT/GET) that have been shown to do many patients serious harm.

**Dr Crawley** is also a Medical Adviser to the Association for Young People with Myalgic 'Encephalopathy' charity (AYME) that has assiduously promoted the psychosocial regimes of CBT/GET and that has in turn endorsed and promoted the Royal College of Paediatrics and Child Health Guidelines on CFS/ME. These have been roundly criticised and proscribed by child patients themselves, their families and health advocates.

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Details of **Dr Frederick Nye** and his involvement with ME/CFS are very well documented in the paper submitted by the 25% ME Group for the Severely Affected charity in its Response to NICE over these Draft Guidelines that states:

"**Dr Fred Nye** is a consultant physician and "Clinical Champion" of the Liverpool "CFS" Clinical Network Co-ordinating Centre, whose advertisement for therapists informed applicants that "CFS" patients have perpetuating illness behaviour; that they experience barriers to understanding; that there can be significant barriers to accepting the changes needed in behaviour, which have to be overcome in therapy in order to facilitate a successful outcome; that the Fatigue Therapist will be required to modify patients' predisposing personality style and provide motivation to patients with CFS; that some clients may be resistant to working in a psychological framework and that there may be verbal aggression (Chronic Fatigue Treatment Service: Ref: 2570. Closing date: 31st January 2005). Following the resultant distress and offence to patients, Nye apologised publicly and the advertisement was withdrawn but the question remains how, under Nye's leadership, such an advertisement came to be issued in the first place."

**Dr Nye** has been a supporter of the psychiatric paradigm on ME/CFS throughout all his dealings with ME/CFS labelled patients.

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The only neurologist on the Guidelines Development Group, **Dr Richard Grünewald**, is a Consultant Neurologist at the Royal Hallamshire Hospital in

Sheffield. A dedicated supporter of Somatoform Disorders, **Dr Grünewald** has produced work supporting and extensively referencing the work of Professor Simon Wessely, head of the Wessely School psychiatrists. (Functional symptoms in neurology: questions and answers, Journal of Neurology Neurosurgery and Psychiatry 2005;76:307-314 © 2005). **Dr Grunewald** has also written on 'fatigue states' and is Associate Editor of the Behavioural Neurology Journal that explores abnormal human cognition and behaviour, amongst his other activities.

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**Page 11 – From [The One Click Group Response – NICE Guidelines](#) (Full Updated Text)**

**Miss Amanda O'Donovan**, is a Senior Clinical Psychologist at St Bartholomew's Hospital. Barts Hospital contains the CFS/ME Centre that has recently been the subject of an intense media campaign designed to hype and propagandize the services of psychiatrist Peter White, leader of the scientifically fraudulent PACE trial (See One Click Presentation to Gibson ME/CFS Parliamentary Inquiry, Appendix 1). Ms. O'Donovan stated in an interview carried out by the charity Action for ME (AfME) that sells these CBT/GET treatments direct to the public: "Graded activity can be a useful addition to CBT..." Other AfME interviewees on this occasion were Louise Ritson and CBT Psychotherapist and Clinical psychologist Dr Hazel O'Dowd. (See References).

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**Dr Alastair Sainthouse** works as a Consultant Psychiatrist at King's College, London in the Chronic Fatigue Research and Treatment Unit, London, with Professor Simon Wessely, the leader of the psychiatric lobby in the United Kingdom. The Head of Services is Professor Trudie Chalder.

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**Dr Julia Smedley**, Consultant Occupational Physician, Southampton University NHS Trust, has been closely involved in the production of the document entitled 'Occupational Aspects of the Management of Chronic Fatigue Syndrome: a National Guideline' (DH Publication 2006/273539 [http://www.nhsplus.nhs.uk/clinical-guidelines/Docs/273539\\_CFSyndrome.pdf](http://www.nhsplus.nhs.uk/clinical-guidelines/Docs/273539_CFSyndrome.pdf)) that has been simultaneously launched with these NICE Draft Guidelines. The content of this document is reflected by the fact that its own Guideline Development Group included Professor Trudie Chalder, with its External Assessors as psychiatrists Professors Michael Sharpe and Peter White, all of whom believe that ME/CFS is a Somatoform Disorder with the concomitant effect of labelling ME/CFS patients as mentally deviant. **Dr Julia Smedley** is thanked for her contribution to this document displaying overt psychiatric bias and it is announced: "We are grateful to the following colleagues who have commented on various sections and drafts of the manuscript: .....**Dr Julia Smedley**, Consultant Occupational Physician, Southampton University NHS Trust."

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**Page 12 – From [The One Click Group Response – NICE Guidelines](#) (Full Updated Text)**

**Dr David Vickers** is a Consultant Community Paediatrician in Cambridge who was involved as a Delphi Participant in the development of the RCPCH Guidelines in ME/CFS children that have been so roundly condemned due to the overt psychiatric bias of the treatments recommended for children that have never been scientifically tested on them. Dr Vickers works in Child Protection for the Cambridgeshire Local Safeguarding Children Board. **Dr Vickers** also works with Dr Peter Lachman, a designated Child Abuse specialist and an advocate of the methods of the disgraced Professor Sir Roy Meadow and Dr David Southfield in relation to Munchausen Syndrome by Proxy/FII, who have both now been disciplined by their professional body and the subject of much litigation. **Dr Vickers** and Lachman co-authored the paper entitled 'The national service framework for children' doi: 10.1136/bmj.329.7468.693 BMJ 2004; 329; 693-694.

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**Page 12 – From [The One Click Group Response – NICE Guidelines](#) (Full Updated Text)**

**Mrs. Gillian Walsh** is the Network Co-ordinator Manchester Clinical Network, Manchester. This CFS/ME Centre is yet another on the list that has been condemned by ME/CFS patients. A sufferer writes to RiME - Campaigning for Research into Myalgic Encephalomyelitis: "... everything about the Manchester CNCC suggests a stitch-up. The leading figure in the process is a psychiatrist Dr L. He appears to promote a psychosocial model of ME which fits in nicely with govt guidelines. Once again ME patients, those who suffer 24/7, are neglected and sidelined. Well done to the new Manchester Group for challenging what is happening here ..."

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**Mrs. Carol Wilson** is the Lead Occupational Therapist Cornwall CFS/ME Service, Falmouth. **Mrs. Wilson** is yet another individual involved in the production of the overtly psychiatrically biased RCPCH Guidelines on ME/CFS labelled children. Carol Wilson works closely with Professor Anthony Pinching, Chair of the CFS/ME Investment Steering Group and, as stated by the Royal Cornwall Hospitals NHS Trust, is the Lead "in Occupational therapy, focusing on activity management and adjustment .... linked to existing community rehabilitation teams."

**5.2 Patient Representatives**

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In addition, the three so-called Patient Representatives on the Guidelines Development Group (GDG), **Mr Richard Eddleston**, **Ms Ute Elliot** and **Ms Tanya Harrison** of the BRAME organisation, whose organisation is doubly represented on the Guidelines Development Group and Stakeholder Group, have failed to represent the concerns of ME/CFS patients either accurately or fairly. They have failed in their duty throughout.

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## 7. VIRAL AND BACTERIAL TESTING

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Page 16 – From [The One Click Group Response – NICE Guidelines](#) (Full Updated Text)

This issue of Lyme Disease/Borreliosis and ME/CFS and lack of adequate testing for patients is particularly pertinent in line with the recent [BADA-UK Statement](#) (Borreliosis & Associated Disease Awareness, Registered Charity No. 1113329) that included words from Dr Darrel Ho-Yen, the **self-styled Lyme Disease 'expert'**, head of Microbiology at the Raigmore Hospital, Inverness, Scotland who admitted possible figures of ME/CFS misdiagnosis that run into the thousands.

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**Key Statement:** In this Version September 2006 of these NICE Guidelines and through the Guidelines Development Group consensus refusal to allow bacterial and viral testing upon symptoms onset, NICE is deliberately placing the lives of patients at risk, with the full knowledge of the suffering and sometimes death that this will inevitably cause.

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### 7.1 LTT-MELISA Test for Borreliosis

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When the HPA that carries out the highly flawed **and disreputable** Lyme Disease/Borreliosis testing in the UK has been challenged as to its competency in the past in regard to testing outside the NHS two tier system and PCR (polymerase chain reaction), its response has been to cast doubt on other methodologies. In order to protect its reputation, it has even gone so far as **to employ execrable medical and political tactics** by maintaining that other laboratories concerned are disreputable and subject to closure shortly.

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## APPENDIX 1 – ME/CFS INFORMATION AND EVIDENCE

1. The One Click Group Presentation to the Gibson ME/CFS Parliamentary Inquiry, 27 April 2006. Available at the Parliamentary Inquiry website at: <http://www.erythos.com/gibsonenquiry/PresDocs.html>

ANGELA KENNEDY

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Page 35 – From [The One Click Group Response – NICE Guidelines](#) (Full Updated Text)

There are broadly two contesting paradigms of ME/CFS: the neurological (biomedical) paradigm, and the psychiatric paradigm. The psychiatric paradigm in Britain is supported by various researchers such as Simon Wessely, Peter White, Michael Sharpe, and Elena Garralda, among others. It has been demonstrated to have serious theoretical, methodological **and ethical** flaws.

Proponents of this paradigm refuse to recognise the WHO ICD-10 neurological classification of ME/CFS. **Indeed, they unilaterally misrepresented the term Chronic Fatigue Syndrome as being classified as a mental disorder in the ICD-10, wrongly advising the British government. This was corrected by the Countess of Mar during a House of Lords debate in 2004, with confirmation by the World Health Organisation.**

**JANE BRYANT:**

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From the scientifically unproven belief system of this psychiatrist and the group that surrounds him, over £11.1m of British taxpayers money has flowed to set up the methodologically **and ethically** flawed psychosocial PACE and FINE trials being conducted at these 'CFS/ME' Centres primarily run by the psychiatrists for psychiatric benefit. These are the 'CFS/ME' Centres that have been thoroughly condemned by ME/CFS patients' right around the United Kingdom as has been evidenced, as just one example, by the many letters from patients sent to RiME – the group for Research into Myalgic Encephalomyelitis.

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The enormous irony **and scientific fraudulence** of the PACE trial is the way that it has been deliberately structured using the outdated and superseded Oxford criteria for patient inclusion into this trial purely to enhance the numbers recruited and to include patients suffering from Idiopathic Chronic Fatigue, a mental disorder classified as such under F48 that is entirely different from ME/CFS. The Oxford criteria specifically EXCLUDE patients suffering from a neurological disorder that ME/CFS IS as defined by many international experts and the World Health Organisation.

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The PACE trial, as delineated in The PACE Report produced by One Click, is a deceit and scandal of massive proportions as has indeed been written up in the Independent national newspaper in 2004. The PACE and FINE trials are clearly little more than job providers for the psychiatrists that are running them who operate on the basis of a misguided but entrenched illness belief system for which there is absolutely no scientific basis, that ME/CFS is a mental disorder, not the neurological illness that it is, as defined by the World Health Organisation. Is it ethical for people with proven commercial interests in these studies to be designing and running these trials, give the proven evidence of their personal commercial interests in the desired outcome of these trials?

**ANGELA KENNEDY**

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**Page 37– From [The One Click Group Response – NICE Guidelines](#) (Full Updated Text)**

We bring to the Group's attention the TYMES Trust Dossier 'The Forgotten Children', the Panorama Survey, and the **Ean Proctor** Scandal, in which a semi-

paralysed 11 year old ME/CFS diagnosed child was thrown into a swimming pool to see if his paralysis was genuine. The child sank. These are just a few examples of the mistreatment that sufferers, especially children, have had to endure as a result of the psychiatric paradigm.

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## **2. A SHORT SUMMARY OF THE PSYCHIATRIC PARADIGM OF ME/CFS**

**By Angela Kennedy, 18 January 2005**

**Available on The One Click Group website:**

[http://www.theoneclickgroup.co.uk/documents/ME-CFS\\_docs/THE%20PSYCHIATRIC%20PARADIGM.pdf](http://www.theoneclickgroup.co.uk/documents/ME-CFS_docs/THE%20PSYCHIATRIC%20PARADIGM.pdf)

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Another example of this position was illustrated, for example, when proponents of the psychiatric paradigm unilaterally (and incorrectly) represented the term Chronic Fatigue Syndrome as being classified as a mental disorder in the ICD-10, and advised the British government that this mis-classification was in order, until the British Government was corrected by the Countess of Mar during a House of Lords debate in 2004, with confirmation by the World Health Organisation. (Footnote 1)

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## **APPENDIX 2 – ME/CFS, Lyme Disease/Borreliosis**

### **Contents**

#### **1. BADA-UK STATEMENT**

**ALL PATIENT CASE HISTORIES EXPUNGED BY NICE >**

**Pages 57 – 64, From [The One Click Group Response – NICE Guidelines](#) (Full Updated Text)**

#### **~~2. Letters/Case Histories From Patients~~**

**~~— 2.1 Katrina Anderson~~**

**~~— 2.2 Nigel Hall~~**

**~~— 2.3 Peter Kemp~~**

#### **2. Letters from Patients/Case Histories**

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We have many Case Histories available from patients. Further Case Histories and letters are available upon request. In this Appendix we provide but a few verbatim examples.

#### **2.1 From Katrina Anderson**

**26 October 2006**

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**Page 57 – From [The One Click Group Response – NICE Guidelines](#) (Full Updated Text)**

## **To Whom It May Concern**

I was bitten by a tick in 1991 and shortly thereafter my health began to deteriorate. I attended my GP's surgery, described my symptoms of pain and fatigue, whilst at the same time pointing out a small hole in at the top of my left leg which I now know to be the tick bite.

The GP knew nothing of tick-borne infections, and as a result, for the next two years I underwent a barrage of tests by the NHS to rule out other known medical conditions. Throughout this two-year period I was given a variety of diagnoses such as palindromic rheumatism and Myalgic Encephalomyelitis (ME), all of which I knew did not fully explain my symptoms. After two years of inconclusive testing I eventually began to doubt my own sanity and asked to be referred to a psychiatrist.

This shocked my GP into renewed efforts to try and understand the cause of my illness, and out of desperation, as apposed to inspiration, he referred me to the Regional Infectious Disease (ID) Unit at my local hospital.

I was very quickly, and luckily, diagnosed with a positive Lyme disease blood test. I say luckily as the form of testing offered within this country is woefully inadequate, and the majority of the medical professions understanding of such infections is even less well founded. The feeling of relief that I felt at that time was incredible, I finally had a reason for my ill health, I wasn't just imagining it.

Had only my GP been better informed of the effects of tick-borne diseases the NHS would not have been required to finance such a prolonged, and expensive, process of elimination.

Today, it would seem that a great majority of the medical profession still remain ignorant to the effects of all tick-borne infections, and the testing for such infections is still woefully inadequate. Yet it would seem that this is of no consequence to NICE, who without a shred of scientific evidence or reasoning, have deemed it appropriate, and cost efficient, to deny such testing to all ME/CFS patients.

Had this illogical and unfounded edict been in place when I first fell ill I dread to think what cost this would have had on my personal health? I would still be suffering under the management of my physical symptoms with treatment regimes such as GET & CBT, and getting nowhere fast, instead of returning to work and being a contributory member of society, as all those with ME/CFS wish to be.

The World Health Organisation recognise ME/CFS to be an illness of bacterial/viral origin. Dr. Ho-Yen recognises that even with such unreliable blood tests as those that are available today, 5% of patients referred to him as having ME/CFS test positive for Lyme disease/Borreliosis.

The majority of patients diagnosed as having ME/CFS have most likely never been offered testing for tick-borne infections, either in the six month period leading up to their diagnosis of ME/CFS, or at any time thereafter.

These new NICE guidelines will ensure that they never do, and are more representative of clinical exclusion, rather than clinical excellence.

**Katrina Anderson**

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**2.2 From Nigel Hall, Sheffield**

**30 October 2006**

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After struggling with extreme exhaustion, chronic back pain and frequent migraines for about three years, I was diagnosed with CFS in 1998. My GP was unable to recommend any treatment except anti-depressants which I have now been taking for several years. I did have an (inadequate) NHS test for Lyme Disease, but the result was negative.

However following a private test for Lyme Disease two years ago I was diagnosed with Chronic Borreliosis. Although at the time my GP seemed willing to go along with this diagnosis, he has since withdrawn his co-operation by refusing to prescribe the drugs recommended by my private specialist.

I cannot afford to fund private prescriptions, and therefore I have become resigned to leading a life severely restricted by my constant battle with pain and fatigue. I am now 56 and, unless the NHS is prepared to abide by its duty of care to me, I do not expect to be able to work again.

Despite my problems I always try to stay positive, too much so as I often suffer the delayed consequences of failing to strictly pace myself. CBT would therefore be of no benefit to me, and GET could make my condition considerably worse by forcing me to function outside my tried and tested limits.

ME/CFS is a neurological condition which urgently needs bio-medical research and treatment, and most definitely *not* psychological intervention. Therefore this appalling decision by NICE amounts to a life sentence of suffering for the 260,000 or so people who have ME or CFS. It is a disgrace.

**Nigel Hall  
Sheffield**

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**2.3 From Peter Kemp**

**9 October 2006**

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**Page 59 – From [The One Click Group Response – NICE Guidelines](#) (Full Updated Text)**

**COMMENT**

In their Draught Guidelines for ME/CFS the National Institute for Health and Clinical Excellence (NICE) have stated: [\[0\]](#)

1.2.2.3 The following tests should not be done routinely.

- Serology testing for chronic bacterial infections (for example, borreliosis)[sic] in the absence of any indicative history.

What is meant by 'indicative history'? If they mean patients with a history of the symptoms of borreliosis then it would seem that many people who are, or could be diagnosed with ME/CFS have a long and convincing 'indicative history'. They would therefore require testing for the bacteria.

Borreliosis is difficult to diagnose[23][24][27a] and can be mistaken for other conditions.[3a][25] The symptoms of ME/CFS, and borreliosis appear the same in many respects.[15][16][17][18] I imagine it is for this reason that the famous microbiologist, Dr. Ho-Yen[14] routinely tests all his patients with ME/CFS for Lyme disease (borreliosis caused by certain strains of the bacteria).[20]

Perhaps 'indicative history' means an erythema migrans rash? The rash is thought by some to occur in only around 50% to 80% of people with Lyme disease[1][2][3][29] and is often so indistinct that it is easily overlooked or mistaken for something else.[4][19] The Health Protection Agency (HPA) state that 42% reported an erythema migrans rash.[10a] The National Guidelines Clearinghouse observe; 'The EM rash may be absent in over 50% of Lyme disease cases.'[29]

Could NICE mean that people who were bitten by a tick have an 'indicative history'? Many people with Lyme disease do not recall being bitten by a tick.[5][6][7][8][9] The HPA figures show that only 55% reported a tick bite.[10a]

Maybe 'indicative history' means people who have been somewhere where Lyme disease is known to be endemic? In England and Wales Lyme disease is not a notifiable illness,[10] so nobody actually knows where it is endemic. The Health Protection Agency receive voluntary reports of borreliosis cases, which their estimates suggest might be around 22% to 36% of the total number of annual cases.[10] The HPA state, 'Cases have been reported from most counties in England and Wales'.[10]

Maybe 'indicative history' means people who have been somewhere where the tick *Ixodes Ricinus* (a common vector for borreliosis in the UK) are known to occur. An HPA map of "'Known" Distribution of *Ixodes ricinus* ticks', shows the tick to occur in most counties in England and Wales.[10b] Neither are the ticks confined to the countryside, NHS Direct note; 'they can also be found in some parks'.[27]

How many doctors in England and Wales will know what an 'indicative history' of borreliosis is? My GP was quite frank about never having heard of borrelia or Lyme disease. The Benefits Agency doctor I saw a few weeks ago was equally innocent of any knowledge of the disease. The consultant microbiologist my GP referred me to some months ago had heard of Lyme disease but admitted that he knew nothing about it. Perhaps the 'absence of any indicative history' refers to doctors, not their patients.

NHS Direct remark on Lyme disease; (after erythema migrans rash) 'Other common symptoms with early Lyme disease include tiredness, headache, joint pains, and flu-like symptoms'.[27] All of these symptoms are also very common in ME/CFS. The symptoms of the two illnesses are so similar that I find it easy to

conceive that in the 'absence of any indicative history', persons with borreliosis could be misdiagnosed with ME/CFS.

My impression is that 'Indicative history' in relation to borreliosis is a misleading phrase that should not be used in the NICE guideline without qualification and a full explanation taking into account the authoritative references provided

17 years ago I was diagnosed with M.E. This year I had the 2 stage, ELISA / Western Blot blood test for borreliosis. It was negative. This was no great surprise as the unreliability of these tests have been noted.[\[3a\]](#) The National Guidelines Clearinghouse observe; [\[29\]](#)

The two-tier diagnostic criteria, requiring both a positive enzyme-linked immunosorbent assay (ELISA) and western blot, lacks sensitivity and leaves a significant number of individuals with Lyme disease undiagnosed and untreated.

In a study of 90 patients, Tylewska-Wierzbanowska and Chmielewski concluded that: [\[28\]](#)

There is no correlation between the level of antibodies (ELISA), the number of protein bands (Western blot) and the presence of spirochetes in body fluids (culture and PCR), indicating that in addition to serological testing the use of PCR and cultivation in the diagnosis of Lyme borreliosis should be recommended.

Using my own microscope I have been able to see and film borrelia bacteria in a tiny periferal blood drop (see [\[26\]](#)). I find it very painful to think that a few weeks of antibiotics at the beginning of the illness might have saved me from 17 years of hell. I do not blame anyone for failing to diagnose me. I do not doubt the dedication and skill of the doctors that investigated me when I was first ill. Borreliosis was simply not thought of back then.

Things are somewhat different now. A great deal of research has provided a broad knowledge base for borreliosis and other tick-borne infections. It is perhaps, understandable that some doctors are still unfamiliar with borreliosis as this disease has not yet been brought to their attention. A major institution such as NICE should not require such latitude and might be expected to avail themselves of the latest information before referring to borreliosis in their draught guideline for ME/CFS. NICE might also consider it part of their duty to make doctors aware of this disease that can so easily be mistaken for ME/CFS.

NICE guidelines carry weight. If the current draught comes into force without modification the consequences could be terrible for many unfortunate people. NICE state that; 'Once NICE publishes clinical guidance, health professionals and the organization that employ them are expected to take it fully into account when deciding what treatments to give people.'[\[13\]](#) and; 'In general, doctors, nurses and other healthcare professionals in the NHS are expected to follow NICE's clinical guidelines.'[\[12\]](#)

How many people diagnosed with ME/CFS actually have borreliosis? How many people face years, decades or perhaps the whole remainder of their life doomed to suffering and loss because they have a bacterial infection? An infection that NICE propose discouraging doctors from testing for, even when their patients have clearly indicative symptoms.

Bacteria have been visible to microscopy since the 1680's.[11] With a little practice, the right equipment and a suitable technique; seeing borrelia with a microscope is not difficult or time consuming. It is a method that might usefully supplement serological testing and other diagnostic means to identify borreliosis.

Two major research projects conducted for the U.S. Centers for Disease Control by Fukuda *et al*.[21] and Reeves *et al*,[22] make it clear that a significant challenge to the progress of research, diagnosis and treatment of ME/CFS is identifying exclusionary illnesses and defining subgroups. NICE have the opportunity to make a valuable contribution to this field by recommending a broad approach (symptoms, serology, microscopy) for identifying borreliosis in people who could be misdiagnosed with ME/CFS.

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