Jane Colby

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If you were hoping to chat to me after the Judicial Review of the NICE Guideline on CFS/ME in the Royal Courts of Justice, I apologise.

Two consecutive days of getting up before dawn and standing in rush hour trains took its toll, as it must have on all who attended. One day was manageable, but after the second I faded. I sat in a cafe while commuters battled their way home. It's the day after the day after that gets you, isn't it? Not the next day, when you are just washed out and convincing yourself that this is as bad as it gets...

Half-way through the following weekend, I started feeling 'normal', having slept for nine hours. That word 'normal' is instructive. For two days I was a normal commuter, jammed in carriages, like the proverbial sardine. I dealt well with the steps, steps and more steps - London is a warren of them - but repeatedly lost myself in the court building as I have precious little sense of direction since the ME. I was steered back on track by the Trust's Chair of Trustees. Once, I worriedly queried our route: 'I've never been down this corridor before...' Wrong! And despite how much fitter I have become over these past few years, my store of energy ran out like the Thames with the plug pulled.

We now know that NICE has won the case. I feel for Kevin Short and Doug Fraser, the two committed and courageous patients who mounted this legal challenge. It was right that the Guideline was challenged and I count it a privilege to have provided Witness Statements at their request. Until we have proper recognition of classic ME any official body would do well to understand that patients will not easily lie down and submit to what they sincerely believe to be misguided treatment recommendations being issued to their doctors.

The case may be over, but the problem remains. To quote the ME Association: 'People with ME/CFS now face a situation where doctors will continue to recommend two forms of treatments that many people with the illness find ineffective or even harmful.'

The Judicial Review has highlighted serious differences between patient charities. Almost all supported the legal challenge. Action for ME and AYME did not. Their outspoken backing for NICE has gone down like a lead balloon with the wider ME community.

In 2004 I was invited to address the Cross-Party Group in the Scottish Parliament. In the course of my speech I showed how patient groups who are too concerned to avoid rocking the boat with the medical establishment end up compromising themselves. I gave clear examples of where that had happened. In the aftermath of that speech, after a crisis meeting of the ME Alliance (now superceded by Forward-ME) all Alliance members, including the Trust, got together to produce a joint report *ME Diagnosis: Delay Harms Health*. It now looks as if 2009 will have to be another year of plain speaking.

This article was first published in March 2009 as an email Alert. Register for our Alerts at www.tymestrust.org.

Enteroviruses Persist in Muscles

This 2003 paper is newly relevant in view of recent developments in CFS/ME (page iv). The theory that enteroviruses can persist in muscles has been ridiculed; many discoveries are, before becoming mainstream. This research supports the evidence for enteroviral persistence in many diseases.

Enterovirus RNA has been found previously in specimens of muscle biopsy from patients with idiopathic dilated cardiomyopathy, chronic inflammatory muscle diseases, and fibromyalgia or CFS. These results suggest that skeletal muscle may host enteroviral persistent infection. To test this hypothesis, we investigated by reverse transcription-polymerase chain reaction (RT-PCR) assay the presence of enterovirus in skeletal muscle of patients with chronic inflammatory muscle diseases or fibromyalgia/chronic fatigue syndrome, and also of healthy subjects.

Three of 15 (20%) patients with chronic inflammatory muscle diseases, 4 of 30 (13%) patients with fibromyalgia/CFS, and none of 29 healthy subjects was found positive. The presence of VP-1 enteroviral capsid protein was assessed by an immunostaining technique using the 5-D8/1 monoclonal antibody; no biopsy muscle from any healthy subject was found positive. The presence of viral RNA in some muscle biopsies from patients exhibiting muscle disease, together with the absence of VP-1 protein, is in favor of a persistent infection involving defective viral replication.

Douche-Aourik, F. et al *Detection of enterovirus in human skeletal muscle from patients with chronic inflammatory muscle disease or fibromyalgia and healthy subjects.*
Journal of Medical Virology, 2003, 71, 540-547.

CFS Patients Will Be Misdiagnosed with Depression

The Centers for Disease Control and Prevention (CDC) recently developed an empirical case definition that specifies criteria and instruments to diagnose chronic fatigue syndrome (CFS) in order to bring more methodological rigor to the current CFS case definition. The present study investigated this new definition with 27 participants with a diagnosis of CFS and 37 participants with a diagnosis of a Major Depressive Disorder.

Participants completed questionnaires measuring disability, fatigue, and symptoms. Findings indicated that 38% of those with a diagnosis of a Major Depressive Disorder were misclassified as having CFS using the new CDC definition.

Given the CDC's stature and respect in the scientific world, this new definition might be widely used by investigators and clinicians. This might result in the erroneous inclusion of people with primary psychiatric conditions in CFS samples, with detrimental consequences for the interpretation of epidemiologic, etiologic, and treatment efficacy findings for people with CFS.

Jason et al. *Evaluating the Centers for Disease Control's Empirical Chronic Fatigue Syndrome Case Definition.*
Journal of Disability Policy Studies 2008,
doi:10.1177/1044207308325995
First published October 21, 2008

Reminder : No Symptomatic Improvement with Melatonin

In 2002 a study by Williams et al found that neither melatonin nor phototherapy (light therapy) were effective for CFS. The authors stated: 'Neither intervention showed any significant effect on any of the principal symptoms or on general measures of physical or mental health. Compared with placebo, neither body temperature rhythm nor onset of melatonin secretion was significantly altered by either treatment...' Williams, G. et al, *Eur J Clin Invest* 2002 Nov; 32(11): 831-837.

In ME the hypothalamus gland is dysfunctional, disturbing circadian rhythm (day/night sleep/wake patterns). The pineal gland, which produces melatonin, appears unaffected. Treatment with melatonin is therefore unlikely to produce results and there are potential hormonal side-effects.

Focus On

Special Problems of Children with ME/CFS and the enteroviral link

The *Journal of Clinical Pathology* has kindly allowed my review of ME in children, which they commissioned and published in 2006, to be republished at www.tymestrust.org. You can now find it on the publications page, entitled *Special Problems of Children with ME/CFS and the enteroviral link*.

Such articles can make a big difference. You may remember parent Karen Mason writing how her daughter's social worker had printed copies of the Trust's professional guide, *The SENCO's Key Role in supporting pupils with CFS/ME*: 'I had been at a very low ebb until I read those guides. Everything in them perfectly described what Bryony had been (and still was) going through, even down to the more seemingly "eccentric" symptoms of ME. In fact it was like reading something that had been written about Bryony. We wasted no time in handing them out to the school and Integrated Support at the following review meeting and I couldn't help but notice that the teacher in charge of Bryony's case seemed to (quite visibly) sit up and take notice when he saw it was written by a former head teacher. Thanks to that report, they have a better understanding of just how much of an impact ME has on the life of a sufferer.'

You can now explain to your doctors about the link with viruses using my review from the *Journal of Clinical Pathology*. It covers:

- Scale of the problem in children
- Pattern of illness in schools
- Clustering of cases
- Energy-efficient education
- Evidence for persistent viral infection

I also discuss making ME a notifiable disease due to the encephalitic nature of the effects on the brain.

www.tymestrust.org/pdfs/specialproblems.pdf

Please note that my research with Dr Dowsett showed that ME is the biggest cause of long term *sickness* absence in schools, *not* the biggest cause of long term absence from schools in general as incorrectly stated by AYME recently.

Publications Available
www.tymestrust.org

Quick Tour of ME Symptoms, Management and Trust Services

In the Spotlight : The Tymes Trust View

Self-Help

Explain Your Abilities

ME ~ and My Friends *(a leaflet for your friends)*

The Tymes Trustcard *(a pass card for school)*

School Examinations and ME - Special Assessment Arrangements

The Essex ME Companion

Diet in ME

Reports

Child Protection Issues

Long Term Sickness Absence due to ME/CFS in UK Schools

ME Diagnosis : Delay Harms Health †

Children and Young People : The Key Points

The Forgotten Children : A Dossier of Shame †

Succeeding with ME *(the Virtual Classroom)* †

Our Needs Our Lives *(on CFS/ME clinics)* †

† presentation copies available

Experiences

Mummies Aren't Supposed To Cry

Whispered Words *(the severely affected)*

For Professionals

Special Problems of Children with ME/CFS and the enteroviral link

ME - The Illness and Common Misconceptions: Abuse, Neglect, Mental Incapacity

The Nightingale Definition of Myalgic Encephalomyelitis (ME)

Professionals Referral Service

Teacher Information on CFS/ME

Back to School?

Pushing the Boundaries in ME/CFS

Ten Points on the Education of Children with ME

The SENCO's Key Role in Supporting Pupils with CFS/ME

The Doctor's Guide to ME in Children and Young People

GPs Good Practice Guide to Education for Children with ME

Physios Urged to Go Cautiously

Implications for Schools of the Chief Medical Officer's Working Group Report on CFS/ME

ME/CFS Guidelines for Educational Psychologists

Care of CFS/ME in Children

Enterovirus Project - Next Steps

From the week the last *Vision* magazine dropped on doorsteps many families have asked about the Trust's enteroviral project with Dr John Chia, so let me give you some more background you may not know yet.

John is a virologist, based in California, specialising in research demonstrating that enteroviruses (related to polio myelitis) are present in the stomachs of a number of people with CFS/ME. What spurred him on was the fact that his own son became ill and he realised that this disease needed to be investigated properly. As those of you who have read my books and articles will know, I worked for many years with consultant microbiologist Dr Elizabeth Dowsett, who is sadly not well enough to work now. I interviewed her for my first ME book published in 1996. Betty gave many lectures explaining the evidence for classic ME being caused by enteroviruses; my own case, which she diagnosed, resulted from such an infection.

Many people with CFS (which stands for Chronic Fatigue Syndrome) will have classic ME, but others will not, because when the term CFS was invented, the criteria for diagnosing it were much wider than the criteria for diagnosing ME. The NICE Guideline on CFS/ME widens them even further, which compounds the problem. How do we know what will help people when they may not share the same cause for their illness? One of my personal priorities is to press for ME to be separated from CFS. I first called for this in my Invest in ME lecture of 2006 and at my request, the Royal Society of Medicine has entitled its June 2009 conference, which I have assisted the Dean to organise, *Medicine and Me: ME and CFS*.

It is hard to find enteroviruses in the body tissues. In the 1900s, American laboratories were unable to reproduce the British findings, which were then widely dismissed. However, in 2004, Dr Chia published a review explaining that the problem was the way in which the American tests had been done. Dr Chia realised that it might be possible to find the viruses in the stomach and he was right. They persist for years. He is now assisting the Trust by processing samples from some of our members which will tell them whether they have enteroviruses in their own stomachs and we can send you the protocol for this test if you wish. It involves taking a sample of stomach tissue, a widely used medical procedure. The sample must be taken according to the protocol and is then sent to Dr Chia's laboratory in California for analysis.

Finding these viruses persisting in the stomach *proves* that something physical is wrong. That may help you to be taken seriously. However, there is no drug yet available to get rid of them, but until a drug company is persuaded that there is real demand for a drug and/or a vaccine, there won't be. It now appears that these same viruses could be involved in causing diabetes in children, and that may help to encourage drugs companies along this route.

If your GP is willing to refer you, the NHS should pay for the procedure (called endoscopy) at the hospital. For the technically minded, the qualitative immunoperoxidase is used to detect the presence of enteroviral protein within the stomach biopsies and detects most of the human enteroviruses, including coxsackie A and B, echoviruses, and enteroviruses 68-71. The antibody used in this assay is specific for enteroviruses, and so far the tests that have been done are positive. Payment for the test to be processed in Dr Chia's laboratory in California is not cheap but according to your answers to a simple medical questionnaire, the Trust may be able to pick up the bill from funds donated for the purpose.

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