# Judicial Review of the NICE Guideline on CFS/ME:

# A response to misleading information on the internet

#### Professor Malcolm Hooper

Jane Bryant's One Click posts of 30<sup>th</sup> July & 1<sup>st</sup> August confirm some of the information already placed in the public domain by Margaret Williams (14/03/09), Kevin Short and Douglas Fraser (17/03/09), and Professor Malcolm Hooper (29/07/09).

Following the Judgment of Mr Justice Simon on 13/03/09 dismissing the Claimants' challenge, Professor Peter Littlejohns of NICE said in a press release: "The Judge recognised the key role that professionals have in contributing to the development of NICE guidelines and therefore understood the vigorous approach NICE took in defending these health experts".

### NICE'S "VIGOROUS" APPROACH

We now know what he actually meant by the term "vigorous". Less than 48 hours before the case was to be heard, NICE ambushed the Claimants' legal team with the threat of a significant wasted costs application. When the hearing began two days later, many observers both lay and legal, were puzzled by the lacklustre presentation of the Claimants' Counsel, Mr. Jeremy Hyam. The commanding performance he had given at the preliminary (permission) hearing before Mr Justice Cranston was now conspicuously absent.

There was a reason for Jeremy Hyam's change of demeanour. He and his instructing solicitor Jamie Beagent of Leigh Day & Co had just been threatened with a career-damaging subsidiary legal action by NICE. This threat was subsequently made good. In July 2009 Mr Justice Simon (the same Judge who dismissed the Claimants' challenge) ordered Leigh Day & Co to pay NICE £50,000 in wasted costs, as compensation for improper conduct of the case.

Ms. Bryant alleges that she too was threatened in a similar fashion by Charles Béar QC, Counsel for NICE - in that One Click's pro bono (ie. free) barrister Conrad Hallin was told that if he proceeded on behalf of One Click and lost, then Ms Bryant might be held personally responsible for all NICE's legal costs.

In another Judicial Review, concerning NICE Osteoporosis guidance that was heard contemporaneously (February 2009) with the ME/CFS legal challenge, similar threats of a wasted costs application were made. The solicitor in the Osteoporosis case was Marie Manley of Bristows, Lincoln's Inn Fields, and the barrister was Martin Chamberlain of Brick Court, Essex Street. These lawyers refused to be browbeaten by NICE and, funded by Servier Laboratories Ltd, that Judicial Review challenge was successful.

In the ME/CFS case however, NICE's intimidatory tactics had the desired effect. Lacking the advantage of a pharmaceutical company's deep pockets, the Claimants' lawyers became thoroughly unnerved. In a seemingly desperate attempt to salvage their own position, they abandoned a substantial part of the Claimants' case. They did this in mid-hearing, without their clients' instructions or knowledge. The first clue the Claimants had of this development was when it was announced in court before lunch on the second day. It would be an understatement to say that their case was by then in some disarray. The failings of the Claimants' lawyers are now the subject of a complaint by the Claimants to the Bar Council Standards Board and the Solicitors' Regulatory Authority.

On behalf of Fraser & Short, Jeremy Hyam presented a limited argument (a) that the composition of the NICE Guideline Development Group (GDG) was biased, to produce a

predetermined result, and (b) that the random controlled trial evidence base produced by the York Review was too weak to support the recommendations of CBT & GET.

Similar issues were explored in the successful Judicial Review of the NICE Osteoporosis guideline, in which conflicts of interest of the Guideline Development Group members were discussed, and Mr Justice Holman found that at one stage in respect of procedure NICE had simply been "going through the motions".

## SEEKING LEGAL AID

In 2008 two separate legal teams found themselves in competition for Legal Aid funding from the Legal Services Commission to challenge the NICE Guideline. There were, however, originally three such cases. In 2007 Stephanie Kennedy, daughter of Angela Kennedy, former co-director of One Click until April 2006, for whom solicitors Hodge Jones & Allen were acting, attempted to bring a Judicial Review which had to be abandoned because Legal Aid could not be obtained. Ultimately, Legal Aid was awarded only to the Fraser & Short team.

On 22<sup>nd</sup> January 2008 Jamie Beagent had written to the Legal Services Commission about Saunders LLP, solicitors acting for One Click, in these terms:

"The proceedings which Saunders LLP issued on the same day as us were set out on a holding basis and included an application for permission to amend and adduce further evidence within 14 days. The reason for this was that the One Click case did not have the necessary expert evidence to make out their claim. As far as we are aware these amendments have not been made and the evidence has not been adduced (certainly we have not been served as we should have been as an interested party). If we are correct in this, then the One Click case is seriously compromised and may presently lack sufficient merit. The Defendant (NICE) has made a specific application in the acknowledgement of service (previously provided to the Commission) that the One Click claim be struck out for this reason.

"Our clients are not in any way related to the activities of the One Click Group".

The Fraser and Short team was legally advised not to seek publicity and took that advice. Subsequently Jamie Beagent was able to write that his clients' conduct had been impeccable throughout.

Since it was unreasonable for two separate cases to be funded by the LSC to challenge the same guideline, and when it became clear that the One Click case was still not ready to be served, on  $23^{rd}$  April 2008 Leigh Day & Co wrote to Saunders LLP saying:

"We are proposing that our clients' case proceeds whilst your client takes a full role in the proceedings as an Interested Party. This will enable the case to proceed 'with evidence on both (cases) being relied upon'. The practical effect would be one which would enable your client to take a full and active part in the challenge and to deploy evidence and legal argument in support of the challenge".

The following day Saunders LLP rejected this proposal, suggesting instead that they should represent all three claimants. They proposed

"that both of the actions are consolidated to include the three Claimants – Bryant, Short and Fraser, with one firm acting for all three clients....We would be prepared to act for all three Claimants in consolidated proceedings and do not foresee that this approach should cause us any difficulty".

It quickly emerged that Jane Bryant's request for joint representation was untenable, for three reasons.

 She had previously lodged an official complaint about Jamie Beagent of Leigh Day & Co with the Solicitors' Regulation Authority, a fact acknowledged by Saunders LLP in their letter to Leigh Day & Co dated 24<sup>th</sup> April 2008:

"Although we have not been involved with the complaint made against your firm to the Solicitors' Regulatory Authority by Jane Bryant, it would appear that there is no prospect of our client working with your firm in the light of this complaint".

On 29<sup>th</sup> April 2008 Leigh Day & Co wrote to Saunders LLP:

"You are right to suggest that it would not be appropriate for this firm to act for Mrs Bryant in light of her complaint to the SRA. You will no doubt be aware that her complaint was considered to be without merit and was not pursued by the SRA. However, in all the circumstances, this firm would no longer be prepared to enter into a retainer with Mrs Bryant in any capacity. Our clients were particularly concerned by the content of Beachcroft's letter in which they draw attention to some of the content of Mrs Bryant's website".

2. When considering Jane Bryant's request for consolidation, the Fraser & Short team had assessed the principal (indeed the only) plank of the One Click case, a witness statement by a general practitioner, Dr. Malcolm Kendrick, challenging NICE's costing for CBT. Having been provided with a copy by Saunders LLP, Dr Kendrick's witness statement was submitted by Leigh Day & Co to two eminent professors of Medical Statistics, who both independently concluded that the Kendrick costing analysis was flawed.

For the reasons stated above, the Fraser & Short team knew that it was impermissible for them to act for One Click in a consolidated action, nor could they pursue the costing aspect in court.

3. In August 2008 they found their decision was well founded, when Ms. Bryant posted a two-page *ad hominem* attack on Kevin Short on her One-Click website. This was hardly evidence of her good faith, nor indeed of any genuine willingness to co-operate with Fraser & Short.

# "DILDO DILLON"

Since One Click was launched, Jane Bryant has venomously and maliciously attacked and harassed many people in the ME world. For that reason she was arrested on 26<sup>th</sup> April 2005 and her computer was seized by police.

Ms Bryant has publicly referred to the Countess of Mar as a "ridiculously jumped-up old boiler".

She has verbally and publicly attacked Dr Vance Spence of the research charity ME Research UK, and bombarded people with exhortations not to support the charity.

She attempted to damage Dr William Weir's medical practice, about which one person wrote: "I think that Ms Bryant's attitude to Dr Weir – and many others – has been distorting, disgraceful and in the spirit of the worst tactics of the gutter press".

She has repeatedly attacked Dr Charles Shepherd of the ME Association both on her website and in personal correspondence.

She has verbally denigrated Jane Colby, CEO of TYMES Trust.

She has denigrated Vivienne Parry of the PRIME project, publicly describing her as "the ubiquitous rent-a-mouth Vivienne Parry" and as "a particularly nasty piece of work".

She has harassed Margaret Williams for years, publicly referring to her as a "twisted, revolting old cow". Eventually Margaret Williams was compelled to instruct Bindmans, a leading London law firm, to seek an injunction against Jane Bryant on the grounds of breach of privacy/confidence, and under the Protection from Harassment Act 1997.

From the beginning, NICE viewed One Click as an organisation which "essentially consists of one individual", who promoted her views "in aggressive and frequently offensive terms". "Those with whom One Click takes issue ... are described as '**demented'**, '**fraudulent'**, '**dishonest'**, '**corrupt'**, perpetrating '**a con'**, or as telling '**lies'** (all these terms are taken from the front page of One Click's website today).

"In the past, our client's Chief Executive has been referred to inter alia as a **'dildo**', a **'disgraceful and disgraced man who could not legitimately find his way out of a paper bag'** and as someone who may be receiving **'kickbacks from the psychiatric lobby'**. This material speaks for itself." (letter from Beachcroft LLP to Leigh Day & Co, 24<sup>th</sup> April 2008).

Having agreed to be involved in the Fraser & Short action as an Interested Party, the One Click case was considered at the end of the second day's hearing. NICE's barrister tried to insist that One Click actually had no right to a hearing, and the Judge was minded to agree. At this point Counsel for Fraser & Short intervened on behalf of One Click, who as a result were then granted a hearing.

MR HALLIN: "On the issue of permission, Mr Hyam has helpfully directed me to the order itself, which is non-specific. Cranston J simply ordered that permission be granted."

Mr. Hallin acquitted himself well, but ultimately the Judge rejected the One Click submission.

# CIARAN FARRELL'S COMMENTARIES

In two recent YouTube videos, Mr. Ciaran Farrell, supporting the view taken by NICE's barrister, has described the Fraser & Short case as a concoction of "conspiracy theories". Mr. Farrell made no contribution to the Fraser & Short campaign, and has access to only a small fraction of the vast amount of legal documentation it generated. He is therefore ill-equipped for his self-appointed role as legal commentator.

In particular, he blames Margaret Williams for the failure of the Judicial Review; he states in one of his videos that she was "the core of the problem" and, using the pseudonym Julia Hamilton, that "Julia Hamilton was <u>caught</u>", clearly implying that wrong-doing had taken place when such is not the case at all. He also said "It is clear that they (i.e. NICE) recorded them" (i.e. her phone calls) and that "there is a good factual base that Julia Hamilton acted inappropriately". He refers to Margaret Williams' action as "nefarious" (that is "villainous"), and states that the Claimants "relied on Margaret Williams to produce their case and Margaret Williams fell down on the job. This Judicial Review was lost due to the unprofessional or should I say antics of Julia Hamilton otherwise known as Margaret Williams".

It would have been unwise of NICE to have recorded telephone conversations without the required warning, and as NICE has not released a transcript of those telephone calls, Mr. Farrell cannot know the content of them, or even if such recordings exist. It must be assumed that Mr. Farrell has chosen to speculate in this manner to lend specious authority to his denigration of the character of Margaret Williams.

The actions of NICE in putting Margaret Williams' private details into the public domain were stringently criticised by the Judge's own lawyer, who was scathing about NICE's improper

behaviour in doing so, especially as NICE's own exhibit makes plain that an ex-directory telephone number was involved and that NICE had given assurances that it would respect this. Not to do so was a blatant breach of the European Commission on Human Rights by NICE.

That the Claimants' lawyers failed to ensure that, following NICE's breach, those details were redacted now forms part of the Claimants' official complaint about their lawyers.

Regarding the Judge's criticism about selective quoting of NICE's witness Professor Anthony Pinching's article published in Prescribers' Journal, Jamie Beagent has acknowledged that the blame was entirely his; on 13<sup>th</sup> February he wrote: "I must accept responsibility for these as I should have checked them carefully before finalising the statement".

#### STATE SANCTIONED MEDICINE?

Ms. Bryant concludes that, such is the power of the NICE monolith, neither patient party could have hoped to win. Perhaps. It is profoundly disappointing that the case got bogged down in a welter of intimidation and tactical manoeuvre. In the words of Jamie Beagent, the Claimants' case was never properly presented or heard: "The worst part of it was that the ME Community was really denied a full and fair hearing because of the distraction over the allegations of bias". (email to the Claimants, 13<sup>th</sup> February 2009).

Doug Fraser and Kevin Short and their supporters fought the case to the utmost of their ability in an uphill struggle to obtain justice for the wider ME community.

Whilst the ME community naturally has an understandable interest in the Judicial Review, we would respectfully ask them to understand that the Claimants and their supporters are restrained by contempt of court laws in what they publish (they cannot, for example, publish any of NICE's documents that were not mentioned in open court, nor the replies to those documents). Furthermore, the Claimants are very ill after what has been a long and exhausting experience.

We would ask for discernment between genuine factual inquiry in contrast to misleading attacks that serve to further divide the ME community and weaken the cause.

It is hard to over estimate the consequences of Mr Justice Simons' ruling: medical adherence to the NICE Guideline will become legally enforceable during 2009. Clinicians must now shrug their shoulders and refer their ME patients for exercise to strengthen their "deconditioned" bodies and, failing that, for psychotherapy to persuade them that they are not in fact physically ill.

The fight against the influence of corporate psychiatry will continue.

We believe that the repeated presentation of evidence-based biomedical information supporting the organic nature of ME, a complex, chronic, multi-system disorder, will ultimately prevail.

It is the very magnitude of the injustice delivered in the High Court that will provide the motivating force.

Malcolm Hooper

5<sup>th</sup> August 2009