



The role of the media in the Stoke CNEP Saga

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As the boxed summary in the first article of this series shows,¹ the way the Stoke neonatal CNEP trial was conducted between 1989 and 1993 was investigated 12 times between 1997 and 2008. Much of the public and political concern that led to this activity was generated by a decade of often sensationalist, irresponsible, frequently misleading and inadequately rebutted journalism.

Early media reports

On 24 March 1997, three months after the research paper about this trial was published in *Pediatrics*,² Carl and Deborah Henshall contacted the *Sentinel*, their local newspaper in Stoke on Trent. They did so because, as Deborah Henshall was to recall before the GMC more than a decade later, 'Having found out that my children had been in a research trial that I had no knowledge of, I wanted to know whether I was the only parent that did not know their child had been used in a research project'.³ Two weeks later, the *Sentinel* reported the Henshalls' claim that their daughter Sofie had suffered brain damage 'caused by slow suffocation' while CNEP was administered in the course of the trial, a trial which, on their account, had been conducted covertly and without their knowledge. The newspaper report noted that the couple's barrister had 'advised [them] that if they establish liability against the health authority they would be seeking substantial damages'.⁴ About a month later, the Henshalls lodged their first complaint with the GMC.³

Two of the Henshalls' children, born 10 months apart in 1992, had been entered into the trial, along with 242 other babies with life-threatening respiratory failure. Both were randomized into the CNEP treatment group. The first, Stacey, was born by Caesarean section at approximately 27 weeks and died two days later; Sofie was born 10 months

later, also by Caesarean, at just over 32 weeks. The couple have six other children, all but the first of whom were born prematurely.³

'We were never told the procedure was part of a trial,' Mrs Henshall was quoted by the *Sentinel* as saying. The newspaper's headline – 'Brain tragedy of baby Sofie. Parents to sue over clinical trial they knew nothing about' – uncritically stated as fact the parents' version of events.⁴

When a national newspaper took up the story some weeks later, it contained new elements.⁵ According to a report in the *Independent on Sunday* on 11 May 1997, sensationally headlined 'Parents say "guinea-pig" trial killed their babies', 'Forty-three premature babies, many only a few hours old, died or suffered brain damage after being used as "guinea-pigs" in a radical hospital experiment'. 'Parents of the babies,' reported the newspaper, 'claim they were not informed of the risks of allowing their children to take part in the trial' and that 'they found out about the experimental nature of the study only after the researchers wrote up their findings in a medical journal'.

'None of the risks,' the article continued, 'was spelt out to the parents', who said they had 'signed consent forms and were shown an information sheet but this claimed that CNEP was safe'. The report recorded that, '[a]mong the parents are Deborah and Carl Henshall from Stoke'. The Henshalls were quoted specifically, Mr Henshall as stating, 'We were not made aware that Sofie's treatment was part of a trial,' while Mrs Henshall was reported as saying, 'I honestly did not know Sofie was going into a research trial ... I was told this was a new, proven ventilator from America which would soon become the normal treatment for premature babies in this country. Now I know this wasn't true.'

Mrs Henshall, said the article, 'gave her consent when Sofie was between two and four hours old

when "I was still under the effects of morphine in the recovery room following a Caesarean".⁵ The day the article was published, the Henshalls wrote a letter to the newspaper insisting that, contrary to the newspaper's suggestion, they had not signed a consent form.

Two days later, on 13 May 1997, the *Telegraph* carried a story stating that the 'parents of a number of babies who allegedly died or suffered brain damage during hospital trials of an experimental ventilator are planning a multi-million pound legal action'. The Henshalls' solicitor was quoted as saying that there were difficult legal hurdles to be crossed. It would be necessary to prove, he said, that the families who consented to the trial had not been properly informed, while 'The major problem is going to be showing the causative link that demonstrates that this machine alone was responsible for what had happened'.⁶

The Henshalls took their case to their MP, Llin Golding, whose intervention with health ministers led in 1999 to the setting-up of an NHS inquiry into research practices at Stoke, headed by Professor Rod Griffiths, then the regional director of public health.

Further new elements are added to the story

To coincide with the publication of the Griffiths report, in May 2000 the *Independent* reported a previously unpublished account of how the Henshalls said they had learnt that their two children had been in a trial. The article described how '[a] chance remark by a doctor at another hospital alerted Carl and Debbie Henshall to the fact that two of their daughters had been involved as guinea pigs in a research trial'.

The couple, reported the newspaper, had 'consulted a solicitor and started legal action against the hospital in 1994. In 1996 the solicitor sent them to a medical expert at St James's Hospital Leeds. He said to us "What do you expect from an experimental treatment?" We said "What do you mean experimental?" Until then we had believed that our daughter had been given the best treatment available'.⁷ Despite occupying a central position in the story, the newspaper apparently did not see fit to approach the doctor in question to see if his recollection of his encounter with the Henshalls accorded with theirs. Certainly he was not quoted

in the article. As it happens, he denies that any conversation in the terms reported by the *Independent* ever took place (personal communication, 26 May 2009).

The *Independent* also failed to address or explain the fact that its article did not chime with the earlier version of the relevant events recorded in its own sister newspaper, the *Independent on Sunday*. Three years before the report of the doctor's 'chance remark' that had allegedly alerted the Henshalls to the fact that their child had been in a research trial, the *Independent on Sunday* reported that the experimental nature of the trial had been discovered by the Henshalls among other parents from a paper published in an American medical journal.⁵

The disciplinary authorities bow to media pressure

There is evidence that from the outset the GMC was more interested in the Henshalls' complaints because of the media coverage they had attracted rather than their intrinsic merits. In an internal email sent to GMC medical and lay screeners in February 1998, a caseworker wrote that while the allegations 'are serious – they include that consent was not properly obtained, that the potential benefits of CNEP were not adequately established before the trial began, and that the test results have been massaged', the case was 'long on speculation, particularly on the part of the Henshalls, but short on evidence, especially of an order which might result in charges against individual doctors'.

Nevertheless, added the GMC caseworker, the couple were 'aggressively mobilising the media, including Channel 4 News, and MPs, including Mrs Llin Golding, on their behalf'. The writer was 'not optimistic about the prospects of proving anything concrete against individual doctors. However ... in view of the serious nature of the allegations, we should respond to the campaign being orchestrated by the Henshalls by asking FFW [GMC solicitors, Field Fisher Waterhouse] to undertake an investigation ...'.⁸

The following year, North Staffordshire Hospital Trust responded in a similar manner to the wider campaign being waged against Dr Southall in relation to his child-protection work, noting that all complaints they received were being copied to the media as well as to a host

of people in Whitehall, including the Secretary of State for Health, the Home Secretary, the Social Services Inspectorate, the Lord Chancellor and Ann Widdecombe MP. As a Trust Board minute on 9 March 1999 noted, the normal response would have been to 'write back and ask for evidence before initiating an investigation. However because the allegations have received widespread distribution ... they warrant further investigation.'⁹

How the central media myth emerged

The central myth at the heart of the media coverage of CNEP, that it had 'killed babies', originated in one of the first articles published about the trial, written by Brian Morgan, a freelance journalist who had already developed a particular interest in Dr Southall and various aspects of his work.⁵

In 1995, before CNEP became headline news, it was Mr Morgan who had first written about the covert video surveillance being conducted by Dr Southall and colleagues to investigate suspicions of induced illness among children who had been referred for apparent life-threatening events. Covert video surveillance conducted in two centres between June 1986 and December 1994 had revealed abuse in 33 of 39 suspected cases. This was work later reported in *Pediatrics* as a 'descriptive, retrospective, partially controlled case study',¹⁰ but characterized by Mr Morgan, writing for the *Times Higher Education Supplement* in 1995, as 'unapproved research'.¹¹

Two years later, Mr Morgan turned his attention to CNEP, which he described in his May 1997 article for the *Independent on Sunday*, headlined 'Parents say "guinea-pig" trial killed their babies', as 'a radical hospital experiment'.⁵ The article began: 'Forty-three premature babies, many only a few hours old, died or suffered permanent brain damage after being used as "guinea-pigs" in a radical hospital experiment'. Nowhere in the article was it made clear that 32 babies who had been entered into the control side of the trial suffered similarly.⁵

The inference – that CNEP had caused these outcomes – was clear, but there has never been any evidence of this;¹² indeed, a long-term study recommended in the report of the Griffiths inquiry later found the CNEP-treated survivors to be mak-

ing progress similar to, and possibly better than that of the conventionally managed children.¹³ But the myth had been born, and it stuck. In 1999, following the news that an inquiry had been ordered into the CNEP affair, the *Independent* reported unequivocally that CNEP had 'resulted in the death or injury of 43' premature babies.¹⁴

The *Independent* was far from alone in the nature of its coverage of the CNEP story and there are many examples of even worse treatment – one of the worst being the 'exclusive' story that appeared in the *Sunday Mirror* in July 2000, beginning with the words: 'Twenty-eight babies died after suffering appalling injuries in controversial experiments carried out by one of Britain's top consultants, the *Sunday Mirror* can reveal today'.¹⁵

MPs highlight the inaccuracy of press reports

In March 2003, Simon Kelner, editor of the *Independent*, was giving evidence during the fifth session of the House of Commons Culture, Media and Sport Committee, which was examining the work of the Press Complaints Commission. At one point, he was asked by Adrian Flook, the MP for Taunton, whether he thought the headlines in his newspaper 'should reflect the words underneath'. Yes, he said, 'I would be distraught if it did not always happen'.

Kelner had walked into a small trap. Earlier that day, the MPs had heard from another witness, Ivor Rowlands, a retired engineer, who had brought to their attention the front-page CNEP article that had been published in the *Independent* in 1999, under the headline: 'Investigation ordered after 28 babies die in hospital experiment'.¹⁴ That headline, suggested Flook, 'was not completely accurate'. Neither, he added, was the one that followed in the *Independent* a year later: 'Parents were misled over hospital trials which killed premature babies'.¹⁶

In the first story, said Flook, the *Independent* had buried 'right at the end' the fact that, despite its headline, the 'rates of death and disability among the 122 babies who received the experimental treatment were no different from those who received conventional treatment'. In fact, he said, 'it was not "28 babies die in hospital experiment", it was 50 in total. Yet they were all premature and there is a mortality of 20–25%, so you would expect something along those lines.'

The headlines, said Flook, were 'very emotive ... bear no resemblance to the story [and] have done a lot of damage to the hospital and doctor concerned'.

Kelner told the committee he did not remember the details of the story.¹⁷

But the inaccuracies keep on coming

Even the finding that CNEP was no more harmful than the standard treatment, which was reported in March 2006,^{13,18} failed to halt the tide. The following year the *Sunday Express* repeated yet again allegations that '[c]hild specialist Dr David Southall ran research on babies which was likely to lead to brain damage or death', while also labelling its reports 'exclusive'.^{19,20} The article that appeared in March 2007, under the headline 'Baby doctor experiment left our girl paralysed', added another twist to the tale, imputing an extraordinary allegation to the Henshalls that 'Women have had unnecessary caesareans to provide premature babies for controversial research'.²⁰

The role of an expert

In the 10-year period 1997–2007 during which the CNEP-related claims repeatedly resurfaced in the media, several newspapers and television programmes made use of a 'medical expert' who always seemed ready to make himself available to speak out against Dr Southall on a wide range of topics, namely, Dr Richard Nicholson, the editor of the *Bulletin of Medical Ethics*. It was, therefore, a matter of some surprise to interested observers that Dr Nicholson was called to give expert evidence at the GMC fitness to practise hearing convened in 2008 to evaluate the charges against three doctors, including Dr Southall, arising out of their conduct of the CNEP trial. This decision to call Dr Nicholson led to some of the more startling findings to be made by the GMC panel in deciding to dismiss all the charges: that Dr Nicholson not only lacked independence and objectivity but over the years had, in the words of the panel, also 'conducted himself as a supporter' of the Henshalls and had shown 'a deep animosity towards Dr Southall' in interviews he had given to the media.^{21,22}

Why the witch-hunt?

The explanation for the CNEP media witch-hunt must lie in part in the potent nature of the more general campaign against Dr Southall, which had been attacking his child-protection work for several years. For some in the media, CNEP was merely a convenient way of extending that campaign to discredit him, but as a result all involved in the CNEP study, and paediatric research in general, suffered severe collateral damage (Modi and Macintosh, submitted for publication). If anyone doubts the potency of such a sustained media campaign, they need look no further than the decision taken by Keele University in 2005 not to offer Dr Southall the customary title of 'professor emeritus' when he retired, largely because the university feared a backlash of 'adverse publicity'.²³

Irresponsible journalism: lessons

The unnecessary and unjustified nature of the whole media-driven CNEP Saga was emphasized in revelatory postscripts written by two of the key players. The report published by Professor Griffiths in 2000 was severely criticized²⁴ and in 2006 he wrote that he had come to look on the task he had been given as 'a poisoned chalice'. In an article for the *BMJ* he also revealed the extent to which media pressure had led to the inquiry. There had, he recalled, been 'repeated headlines' about CNEP, alleging 'that excessive deaths had occurred'. As regional director of public health, he had 'already commented to the media that premature babies of that age had a significant mortality and that the children in the trial had fared no worse than expected'. Nevertheless, 'the story did not go away and local MPs took it up' – and the inquiry went ahead.²⁶

In 2007, the Henshalls' former MP, now Baroness Golding, publicly expressed her regret at the chain of events she had helped to set in motion. In an open letter to the *Sentinel*, she wrote that she wished to apologise to Dr Southall 'and say how sorry I am if my initial concern has given fuel to what can only be described as a witch-hunt, aided and abetted by some professional people who surely should know better'.²⁷

One of the key lessons to emerge from the CNEP Saga is that, left unchallenged, adverse media coverage can have a catastrophic outcome

for medical professionals, institutions, research and, ultimately, patient care.¹ The MP who triggered the initial inquiry and the man who then led it have both acknowledged that it was unchallenged media pressure that set the ball rolling. Internal minutes, memoranda and emails show that it also drove the actions of the hospital in Stoke, Keele University and the GMC.

If those in authority take only one lesson from the costly CNEP Saga, perhaps it should be this: that what interests the public should not be confused with what is in the public interest.

References

- Hey E, Chalmers I. Mis-investigating alleged research misconduct can cause widespread unpredictable damage. *J R Soc Med* 2010;**103**:133–8
- Samuels MP, Raine J, Wright T, *et al.* Continuous negative extrathoracic pressure in neonatal respiratory failure. *Pediatrics* 1996;**98**:1154–60
- General Medical Council. Fitness to Practise Panel: Case of Spencer, Southall, Samuels, day 9, 22 May 2008 Examination and cross-examination of Deborah Henshall
- Blackhurst D. Brain tragedy of baby Sofie. *The Sentinel* 1997 April 9
- Morgan B, Blackhurst C. Parents say 'guinea-pig' trial killed their babies. Now they are going to sue. *Independent on Sunday* 1997 May 11
- Smith M. Parents to sue over injury and death of ventilator babies. *Telegraph* 1997 May 13
- Laurance J. Chance remark alerted parents. *The Independent* 2000 May 9
- General Medical Council. Professor Southall [internal memo]. 10 February 1998
- North Staffordshire Hospital Trust. Board minutes. 9 March 1999
- Southall D, Plunkett M, Banks M, *et al.* Covert video recordings of life-threatening child abuse: lessons for child protection. *Pediatrics* 1997;**100**:735–60
- Morgan B. Babies used in research trials without consent. *Times Higher Education Supplement* 1995 March 17
- Hey E, Chalmers I. Are any of the criticisms of the CNEP trial true? *Lancet* 2006;**367**:1032–3
- Telford K, Waters L, Vyas H, *et al.* Outcome after neonatal continuous negative-pressure ventilation: follow-up assessment. *Lancet* 2006;**367**:1080–5
- Laurance J. Investigation ordered after 28 babies die in hospital experiment. *The Independent* 1999 February 18
- Rimmer A. X-files of the guinea pig babies. *Sunday Mirror* 2000 July 9
- Laurance J. Parents were misled over hospital trials that killed premature babies. *The Independent* 2000 September 8
- House of Commons Culture, Media Sport Committee. Privacy and media intrusion. Fifth Report of Session 2002–3. HC459-II Ev402
- March B. Study vindicates doctor behind baby experiment. *Daily Telegraph* 2006 March 20
- Murray J. Inquest demand over baby deaths. *Sunday Express* 2007 March 4
- Murray J. Baby doctor experiment left our girl paralysed. *Sunday Express* 2007 March 18
- General Medical Council. Fitness to Practise Panel: Transcript, Case of Spencer, Southall, Samuels, day 9, 22 May 2008
- Gornall J. Three doctors and a GMC prosecution. *BMJ* 2008;**337**:a907
- Gornall J. Bad publicity denied Southall a Keele professorship. *The Guardian* 2007 November 8
- Hey E, Chalmers I. Investigating allegations of research misconduct: the vital need for due process. *BMJ* 2000;**321**:752–5
- Griffiths R. CNEP and research governance. *Lancet* 2006;**367**:1037–8
- Griffiths R. On drinking from a poisoned chalice. *BMJ* 2006;**332**:801
- Golding, Baroness. Dr Southall was a rare voice for abused children. *The Sentinel* 2008 January 10