

Summit to save Charlie

Doctors from Pope's hospital and US fly in to assess new brain scans

CHARLIE Gard had his first brain scan since April ahead of yesterday's arrival of the American doctor who wants to save him.

Dr Michio Hirano flew to London from New York and went straight to examine the 11-month-old at Great Ormond Street Hospital (GOSH).

The Harvard-educated neuroscientist - Charlie's last hope - was joined by a doctor from the Pope's hospital in Rome, which is also offering to treat the boy.

They spent five hours at the hospital with him and studied his latest brain scan, taken on Sunday.

Charlie's parents Connie Yates and Chris Gard, of Bedfont, southwest London, were present for the electroencephalogram (EEG), which monitors brain activity.

The results have not been made public but could be crucial in determining his fate. Last night a source close to the family said they 'remain optimistic'. Today

By **Sam Greenhill**
Chief Reporter

the two doctors will return for a make-or-break meeting with GOSH medics. Miss Yates, 31, will be at the discussion about whether her son can be saved, after convincing the High Court judge in the case that she should be there.

Charlie's London doctors say previous brain scans and other tests show he is irreversibly brain damaged and beyond hope.

But Dr Hirano, who specialises in Charlie's rare form of mitochondrial depletion syndrome, says his experimental therapy has a 56 per cent chance of 'meaningful improvement'.

A transcript of the meeting will be handed to Mr Justice Francis, who will decide next Tuesday - ten days before Charlie's first birthday - whether he should be allowed to have the therapy or should have his life support withdrawn so he 'dies with dignity'.

It emerged yesterday that the



Picture: FEATUREWORLD

Last hope: Charlie Gard's parents have begged a judge to allow him to have experimental drugs

judge held an emergency directions hearing over the weekend, believed to be from his home.

Although the case is being held in open court, the media was given no information about the weekend hearing or why it could not wait until the working week. The judge was on leave yesterday and unavailable for comment.

Yesterday, Miss Yates spent all day at GOSH, but Mr Gard was seen arriving shortly before Dr Hirano and a fellow expert from

the Bambino Gesù Hospital in Rome came to examine Charlie. After the five-hour consultation both doctors left by a side exit.

Father-of-two Dr Hirano, 56, whose father was also an acclaimed neuroscientist, is a senior clinician at Columbia University Medical Centre in New York.

A spokesman for GOSH said the two men were welcomed by the hospital's medical director before being shown to Charlie's bedside.

She said each physician was

given an honorary contract granting them the same status as local clinicians, and allowing them to examine the patient and to have full access to records and facilities. 'They will have access to all clinical systems including diagnostic images,' she added.

An EEG Charlie had on March 30 was described as 'very severe' by Dr Hirano at the High Court in April. But he said he would try the experimental drugs as 'the alternative is that he will pass away'.



By **Guy Adams**

Baby's lawyer and her links to euthanasia cheerleaders

EVERY legal professional dreams of being named 'lawyer of the week' by The Times, an honour that brings a set-piece interview in which the newspaper asks such questions as, 'What single law would you enact?'

Six months ago, highly regarded barrister Victoria Butler-Cole found herself in this coveted position. Her answer was that she'd change British law to allow doctors to kill terminally ill patients more efficiently.

'When the Court of Protection decides it's not in a person's best interests to continue to receive artificial nutrition and hydration, it's withdrawn and the person dies slowly of dehydration,' she declared. 'The court cannot authorise a fatal dose of medication instead. To me, that is obviously wrong.'

This viewpoint was entirely in keeping with Mrs Butler-Cole's position as chairman of Compassion in Dying, an offshoot of Dignity in Dying, the charity formerly called the Voluntary Euthanasia Society.

Her links to these organisations have left the parents of Charlie Gard 'astonished' at her appointment as their son's 'voice' in the legal proceedings, representing his court-appointed guardian.

Compassion in Dying does not campaign for assisted dying itself. But as a member of its board since 2013, the 40-year-old barrister is required to 'support the aim' of the sister organisation, which has long campaigned for terminally ill people to be allowed to take their own lives.

Her expertise in this complex and divisive area of medical ethics stems from more than a decade representing hospitals, health authorities, patients and families in what is often a hugely controversial area of the law.

Work frequently takes her to the Court of Protection, where decisions are taken on behalf of patients deemed incapable of deciding important matters for themselves. More often than not, in recent years, she has made headlines advocating for litigants seeking to end a severely ill patient's life.

In May, Mrs Butler-Cole represented a pensioner who asked a judge to let doctors

withdraw treatment from her middle-aged daughter, whose Huntington's disease was in its final stages. (The judgment does not yet appear to have been handed down.)

Five months earlier, she worked for Lindsey Briggs, the wife of Gulf War veteran and former police officer Paul Briggs who had suffered severe brain trauma and five fractures to his spine in a motorcycle accident. Mrs Briggs believed her husband was in a permanent vegetative state and ought to be allowed to die. But doctors said he was minimally conscious and should be kept alive.

The court sided with Mrs Briggs, enhancing Mrs Butler-Cole's reputation as a sharp advocate who, in the words of one legal journal 'takes on major disciplinary hearings and wins them consistently'.

Other high-profile 'wins' came on behalf of the family of a 50-year-old socialite who refused life-saving treatment on the grounds she didn't want to grow old, and for a mother

who wanted her son, who is in his thirties and has Huntington's, to be allowed to die.

The common thread in these cases is of course at the heart of the Charlie Gard controversy. Here, Mrs Butler-Cole belongs to just one of the three legal teams. One represents Great Ormond Street Hospital, another works for Charlie's parents Chris Gard and Connie Yates.

THE third is appointed by Cafcass, a quango that provides a 'guardian' for any child involved in such cases, whose role is to ensure the youngster is safe, and that decisions made about them are in their best interests.

At the request of Charlie's guardian, Mrs Butler-Cole has vigorously argued that the baby has irreversible brain damage and ought to be allowed to die to minimise his



Divisive issue: Victoria Butler-Cole is chairman of Compassion in Dying

suffering. Smart and combative in court, her contributions have at times been highly traumatic for Charlie's parents.

At a hearing earlier this month, the judge thanked Mrs Butler-Cole, only for Chris Gard to immediately respond: 'That's ridiculous. We are his voice!'

In fairness to Mrs Butler-Cole, it should be stressed that, as a barrister, she is not responsible for taking major decisions about Charlie's future.

Her role is to advance the agenda that his legal guardian believes to be in the child's best interest. Her link to Compassion in Dying hasn't prevented her from previously acting for clients who wish to preserve (as well as end) life, either.

In 2012, she represented an NHS trust treating Neon Roberts, a boy with brain cancer. His mother Sally thought conventional treatment would damage him, and proposed alternative therapy. Her estranged husband Ben, with the trust, wanted him to have chemotherapy and radiotherapy. Mrs Butler-Cole's side won, and a year later Neon was reported to be 'clear' of cancer.

This week, a source close to Charlie's parents suggested the involvement of Mrs Butler-Cole, given her role at Compassion in Dying, 'looks like a profound conflict of interest'. Presumably, she would disagree, but revelations about her views on euthanasia will only serve to further inflame emotions in this increasingly febrile case.