Dear Mr Barclay,

You will be aware of the awful tragedy our family is going through since our son Archie suffered severe brain damage in April as a result of an online challenge gone wrong. We are grateful to doctors and nurses at Royal London Hospital for the treatment and care given to Archie in the past four months. However, I am sorry to say that throughout that period, our pain and distress has been being much aggravated by the actions of two or three senior doctors at the hospital, and the management of Barts Health NHS Trust.

From day one, the family as well as the treating clinicians have been put under daily pressure from the Trust to give up on Archie, withdraw life support and let him die. After only three weeks, we were dragged into Court at a few hours' notice. Since then, throughout these three months, we have been rushed from one court hearing to another every few days, having to fight for Archie's life against a generously funded army of lawyers and NHS managers.

Throughout these months, we were never given even a few days space to cope with the family tragedy. You will be aware that our case now is before the UN Committee on the Rights of Persons with Disabilities, who have last night issued an 'Interim Measures' injunction to the UK government to keep Archie alive while the Committee considers the case. Under Article 4 of the Optional Protocol to the UN Disability Convention, the interim measures are binding on the United Kingdom as a matter of international human rights law.

Devastatingly, the Trust's lawyers have responded by telling the family that the Trust intends to defy the UN injunction and to proceed to remove life support from Archie as early as on Monday 1 August.

If this happens, this will be an extraordinary cruelty, and a flagrant breach of Archie's rights as a disabled person. Archie is entitled to have the decisions about his life and death, taken by the NHS and UK courts, to be scrutinised by an international human rights body. Hastening his death to prevent that would be completely unacceptable.

I trust that you will now act immediately, as a member of the government responsible for the NHS, to ensure that this does not happen, and our country honours its obligations under the international human rights treaties which we have signed and ratified.

Christian Concern