

**Neutral Citation Number: [2009] EWHC 3269 (Fam)**

Case No: FD09P01078 Part Heard

**IN THE HIGH COURT OF JUSTICE  
FAMILY DIVISION**

Royal Courts of Justice  
Strand, London, WC2A 2LL  
10 November 2009

**B e f o r e :**

**Mr Justice McFarlane**

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**In the matter of RB (A Child)**

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**WORDS OF ENDORSEMENT**

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## Remarks of Mr Justice McFarlane Re: Baby RB

1. In the autumn of last year, KM and AB, a young couple in their mid twenties, were looking forward to the birth of their first baby. The pregnancy had gone well and no complications were expected. On the 10<sup>th</sup> October 2008, following a normal labour their son, RB was born. It was, however, from the very moment of birth, apparent that their baby was profoundly unwell and could not breathe on his own. He was placed on a ventilator and admitted to the Special Care Baby Unit.
2. Save for a few short attempts which have come to nought, RB has not been able to breathe without artificial ventilation at any point during the 13 months that have now passed since his birth. He is profoundly disabled by a defect which prevents the effective transmission of messages from his brain and nerves to his muscles. It affects every aspect of his physical life. Apart from being able to make small movements of his lower arms and hands, he has little control over his limbs. His face is incapable of expression and his eyelids hang low and are not often open. A tube through which air passes to his lungs passes through one nostril and a feeding tube in the other nostril. His need for breathe is now such that, unless the machine delivers air one every three seconds, his body will go into crisis and decline. Recent attempts to lengthen this period by just one second, have had to be abandoned, such is his need for artificial ventilation from the machine upon which he is, and will always be, totally dependent.
3. It is, I suspect, impossible for those of us to whom such an event has not happened to do more than guess at the impact of it upon these two young parents. In one moment all of the hopes and dreams that they will have had for their expected baby will have been dashed and replaced with a life characterised by worry, stress, exhaustion, confusion and no doubt great sadness.
4. 'Parental responsibility' is the term used in law to describe the role of a parent. During the past 13 months both KM and AB have discharged their responsibility to their son in a manner which has been described by all who have seen it in superlative terms. Dr F, the consultant in charge of RB's care, described the actions of these parents as 'exemplary'. RB's key nurse said of the parents: 'they are brilliant; they are great parents; they love him dearly, are always at his bedside and always want what they feel is best for him'. It is a fact that K and A have spent the most part of each and every day of the last 13 months at RB's bedside, doing what they can to care for him and, when the opportunity arises, to interest and stimulate him, seizing upon any sign of a spark and trying to develop it into something more. They have put their own adult lives on hold. The stress has been immense, it has cost them their relationship, but still they work together and do what they can to support their son. When faced with the awfulness of the situation in which they found themselves, these two young people have stepped up to the plate and discharged the responsibility that life had thrust upon them by each showing 100% commitment to their child in a manner which can only command profound respect and admiration.
5. In the time that has gone by, it has been possible for the medical experts to reach the clearest view that they can as to RB's future prospects. In short terms, the condition from which RB suffers, congenital myasthenic syndrome, is an inherited muscular disorder caused by a genetic defect. The court has heard evidence from Professor

Hanns Lochmuller, one of only three recognised experts in Europe on this condition. He is satisfied that this is the correct diagnosis. CMS covers a substantial number of different genetic defects, each of which produces a malfunction of the neuromuscular junction. Despite much progress in recent years in mapping the genetic causes of this condition, it has not been possible to identify the defective gene in RB's case. Even if identification had occurred the information would be academic unless a drug could be developed to neutralise the misfiring of the chemical message sent by RB's nerves to his muscles. Some such drugs exist but they are specific to the particular chemical abnormality at which they are targeted. Where they work, the court has heard that the effect, which takes place in minutes, is like moving from night to day. The press in recent days has carried stories of such recoveries. RB has been trialled on each of the three known drugs. Tragically he has not shown any effective response and the prospect of effective treatment for him, which would involve both identifying the defective gene and relying upon the development of a new pharmaceutical, must be many years down the line.

6. All involved in RB's care, and principally his parents, have recognised for some time that it cannot be in his best interests for him to remain for the rest of his life as an inpatient on a Paediatric Intensive Care Unit. Until some 10 years ago, the option for patients who required extensive ventilation were limited but, the court has heard, that pioneering work has been undertaken in developing treatment and support that allows some of these patients to leave hospital and live at home. They do so after a tracheostomy operation to their throat, which allows ventilation from a portable ventilation unit. In RB's case the choices for his future are stark. There are only two. One is for his time on the PICU to end in a planned way, with the administration of a large dose of sedative, the removal of the ventilation tube and his consequent death. The other is to contemplate his discharge from hospital on home ventilation after a tracheostomy. At the start of this hearing the treating clinicians and his mother had sadly concluded that the first option was, in the all the circumstances, in RB's best interest. The father contested that conclusion and sought to argue for RB being discharged under the second option.
7. It is neither necessary nor appropriate in these short words of endorsement to descend into the detail of the evidence that this court has heard over the past six days. It is sufficient to say that as each day has gone on the picture of RB and the life, if that is the right word, that he could experience on home ventilation has become clearer. Undertaking a tracheostomy and connecting him to a portable ventilator, rather than being a panacea, would simply open up the potential for him to have to endure a further range of procedures and operations. The very living of life itself, day by day, hour by hour, is likely to be at best uncomfortable for him and, more probably, regularly painful for him. The medical evidence is to the effect that he is likely to feel pain and discomfort in the same manner that any baby does, yet this little boy with his inscrutable features, immobile limbs and soundless voice often gives no outward sign of that which he is feeling.
8. I have total confidence in saying that each of these two parents and each of the treating medical team have done all that they could possibly have done to make RB's life as viable, comfortable and enjoyable as it could be. I am also fully satisfied that the doctors and scientists have investigated each and every option for RB's future treatment in the manner that I have just described.

9. This morning the father has changed his opinion on what he sees as being in his son's best interests. At the start of this hearing last week he came into the courtroom with a comprehensive knowledge of RB and his needs, I, on the other hand, was hearing all of this detail for the first time. In the course of the week, however, I suspect that the father and I have travelled a similar path down the evidential road and have now reached the same conclusion. In doing so I have been very greatly assisted by each and every professional who has played their part in this anxious process. I have been particularly impressed by the obvious care that the treating team at the applicant hospital have provided to RB. This level of care spans the range from the smallest detail of his daily physical care up to and including the obvious thought that they have given to determining the ultimate advice that they have given to these parents and to this court as to RB's future care. The stage has now been reached that all three of the witnesses who are expert in the delivery of respiratory care, Prof H, Dr D and Prof B, are at one in concluding that it is just not in RB's best interests to contemplate a life for him outside the PICU. I found, Prof B's contribution particularly compelling, coming as it did as an independent voice and setting out in a detailed and reasoned manner the benefits and burdens that the future would hold.
  
10. I used the word responsibility at the start of these remarks. It is apt to use it again at their close. AB could, if he had wished, have left the responsibility for taking this decision to the court. He has not chosen to do so. He has, no doubt with a level of sadness that has already been experienced by KM, taken that responsibility upon himself. That he has done so is totally in keeping with the manner in which both he and KM have conducted themselves at every stage of this sad, sad journey. For my part, I agree with the outcome and consider that the conclusion to which they and the clinicians have come is the only tenable outcome for RB, the viability of whose life, from its first moment, has depended upon receiving intensive and invasive care from others.